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ABSTRACT

Twenty presentations from a 1978 conference for parents of children with cancer focus on the teenager and cancer, long term survival of children, the parents and treatment, and practical problems involved. The following papers and authors are represented: "The Role of the Patient Family" (Clark, Fox-Kolenda); "How the Child Perceives Illness and Death" (S. Hostler); "Treatment" (D. Schwartz); "Pastoral Care and the Psychosocial Needs of the Teenager Facing Death" (F. Bender); "Coping--Teenage Panel Discussion" (Sister Margaret Weeke); "Recent Developments in the Treatment of Childhood Cancer" (D. Poplack); "Blood Needs of the Child with Cancer" (C. Jackson); "Prolonged Remissions" (A. Hausen); "Education--The Issues and the Answers" (J. Crockett); "The Child Off Treatment" (M. Wollner); "The Child with Cancer--Achieving Peace of Mind" (G. Jampolsky); "The Parent as Part of the Treatment Process" (J. Wilbur); "Panel Discussion--Parents as Professional Members of the Team" (M. Allen, et al.); "Parental Interrelationships in Living with Pediatric Cancer" (G. Morrow); "Discipline and Training" (B. Lucas); "Cancer and Nutrition" (B. Henkin); "The Cost of Cancer" (J. Black); "The Terminal Child, Relapse" (E. Forman); "Home Care for the Child with Cancer" (I. Martinson); and "Medical/Ethical Problems Associated with Childhood Cancer" (L. Emmerglick). (CL)

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Proceedings of the First National Conference for Parents of Children with Cancer

"Maintaining a Normal Life"

June 23-25, 1978
Marymount College, Arlington, Virginia

Sponsored by the Candlelighters Foundation

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I. About Candlelighters

We are an international organization of parent groups whose children have or have had cancer.

Believing "it is better to light one candle than to curse the darkness," we share these goals--

- to identify patient and family needs so that medical and social systems respond adequately
- to seek consistent and sufficient research funding
- to create networks linking parent to parent, family to family, and group to group
- to exchange information on research, treatment, medical institutions, and community resources
- to provide guidance in coping with cancer's effects on a child, on parents, on a family
- to ease frustrations and fears through the sharing of common experiences

- to break down the social isolation of families
- to become an emotional support system of "second families" to each other

When a child has cancer, the whole family is affected. While the child lives with the stress of sickness and treatment along with the ordinary pressures of childhood, parents strive to keep family life as normal as possible. The problems of coping are many and complex. To whom, and how much do parents tell? How should treatment, discipline, nutrition, neighbors, family, school, finances be handled?

Candlelighters parents share the shock of diagnosis, the concern about treatment, the anxiety of waiting, the despair at relapse, the grief at death, the despondency of loss, the hope of remission, the joy of cure.

Candlelighters support one another in times of need--at diagnosis, before surgery, during hospitalization, upon relapse, as death approaches, or when a child is taken off drugs.

Sometimes, the need may be to help and comfort someone else. Candlelighters care in the unique way only parents of other young cancer patients can.

Family Support

Locally, Candlelighters provide a forum where parents share questions and answers about families living with a young cancer patient.

Groups sponsor 24-hour crisis lines, buddy systems, parent-to-parent counseling, professional counseling, and self-help groups. Candlelighters hold social functions where families meet and relax in a supportive, nonthreatening setting.

Groups may also offer babysitting or transportation; serve as clinic waiting-room aides; sponsor blood banks; foster immune programs, wig banks, in-hospital visitors, or the establishment of Ronald McDonald residences for families of children on extended care away from home.

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Information Services

Local groups present speakers and panels on childhood cancer, maintain libraries and speakers' bureaus, publish newsletters and handbooks of local resources, hold regional conferences, and serve on community boards such as American Cancer Society advisory committees.

Membership

Candlelighters includes over 100 parent groups in the United States, Canada, and Europe.

In addition to parents, membership is open to anyone interested in the control and care of childhood cancer and in meeting the needs of families facing this experience. Medical and psychosocial professionals have joined Candlelighters.

Some groups have youth auxiliaries for teenage cancer patients and teenage siblings of children with cancer.

Minna Nathanson

II. About the Conference

Starting in 1970, almost simultaneous with the beginnings of the National Parents' movement, all letters and phone calls carried the same message from parents: How can we, as parents, best show the "cancer community" at large the things we find most helpful in the treatment and support of families? How can we also achieve the added benefit of meeting each other face to face and exchanging views? Our answer was a National Parents Conference, bringing together a representative cross-section of parents to present their picture of the "caring" system that affected their children and to give parents an opportunity to voice the questions that they have about that system.

How was this achieved? Initially, through the mail. Then finally in 1976 a planning committee met with representatives of parents' groups from many states and the skeleton plan of the conference was laid out. Since it was important that the first conference include something for everybody, the conference was planned as a smorgasbord.

The Foundation is not a fund-raising organization. Hence, the first question was: Could we have a conference without funds? The answer: We could ask the professionals and parents attending the conference to pay their own way and omit honorariums. We are indebted to the local divisions of the American Cancer Society who saw the importance of the conference and agreed to send parent representatives from their states. Many hospitals also

subsidized parent and professional conference expenses. The Metropolitan Washington Candlelighters acted as hosts and coordinators of the considerable work involving the 357 adult participants, 27 teenagers, and 33 children from 27 states who attended the conference.*

One unique aspect of the conference was the selection of professional presenters. All professionals listed were candidates of parent-support groups. Their presence on the program says that these people are not only super "docs," they are human beings. They are helpful in every way--medically and through their support to us and our children. So many candidates were put forth by parent groups, that we could easily have held three conferences simultaneously.

The special parents' perspective was not ignored. Each area of concentration had a parents' reactor panel which was primarily responsible for the parents' view of the presentation made by the professional and addressing questions to the professional.

It will be apparent to anyone reading these proceedings that the conference was a success on an information/education level. What could not be so readily apparent is the great success it was on a personal level. Parents met other parents and exchanged viewpoints with professionals. Our children played, swam, and watched television together. Our teenagers also got to know each other. They had parties and formed new and lasting friendships.

We wish to thank the national office of the American Cancer Society, Inc. and the District of Columbia Division of the American Cancer Society for their invaluable efforts in making the conference a success.

In addition, we especially thank the Office of Cancer Communications, NCI, who viewed the conference as an important source of information valuable to all concerned with pediatric and adolescent cancer. The Office of Cancer Communications provided encouragement, advice, and moral support throughout this endeavor.

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* Special thanks to Julie Sullivan, Grace Ann Monaco, Minna Nathanson, Bob Becker, Jean and Bob Bykowski, Elizabeth Gardner, Al Karr, Mary and Ray Keating, Dave and Joanne Krecke, Susan Lawrence, Jane Lewis, Tom and Millie Pacl, Lou Plaskin, Carey Randall, Doris and John Rodgers and their teenage volunteers, Patsy Rogers, Ginger and Larry Strong, and the Sullivan Family.

Finally, a very special thanks to our teenagers whose insights and zest for life made this conference unique, and most especially to Eddie Kimball of Kansas who passed away shortly after the conference at which he had a long-sought chance to tell his story and have a last adventure.

Minna Nathanson

III. Introduction

Grace Powers Monaco, J.D.

Before introducing the speakers, I would like to say that the conference is like a great big family coming together. If someone had said to me in 1970, when we had three parents' groups, that today we would have over 100 parents' groups in 42 states and Canada and Europe in our communications network, and that next year we will have groups in South America, I would not have believed it possible. If someone had told me a year and a half ago when the idea of a parents' conference was conceived that we would actually be here, I would have found it difficult to believe.

In 1970, when we first got started, cancer was a word that was depressing to everyone. I am not saying that it is not still depressing, but rather that the atmosphere of cancer has changed to living a normal life with cancer. A family can have fun even though they have the obstacle of cancer to overcome. This has become recognized and is not merely the exception. The beautiful thing about all of you who are here, as representatives of parents' groups, is that you have done something to bring hope, joy, and sharing to other people. You are reaching out and expanding that knowledge of maintaining a normal life beyond the frontiers we first got started with. So now we are actually talking about living and not just surviving.

There are very few places we cannot go together, very few places in which we cannot improve things for our children, and very

little that we cannot achieve in terms of what research and application can do if we work together with a common cause and a common voice.

Now, I would like to say a little bit about the people I have the pleasure to introduce.

The unique thing about this conference is that every single participant is someone who was recommended by a parent or parents' group. They are all our friends, our very special people. They are not just the names you see in professional journals, although they are all represented there. They are people who have shown that they know something about humanity as well as good science, and that is very important to us.

IV. The Role of the Patient Family

R. Lee Clark, M.D.
and
B. J. Fox-Kolenda, B.A.

We want to congratulate you and members of your organizing committee for the outstanding program you have put together for the First National Conference for Parents of Children with Cancer. It is a privilege to be with you.

Assume for a moment that you are a child again. Allow your deepest personal longings to assert themselves. What have you craved most, for as long as you can remember? To most of us, the answer would be security--freedom from anxiety about the present and future, freedom from the fear of pain, physical and emotional. This is what your children crave most from you and from us, freedom from fear as each hour goes by--hearing a steady internal rhythmic and reassuring voice saying, "Everything is all right. There is no need to be afraid. I am loved; I am safe. Somebody cares."

Of course, no one is totally safe from fear and pain. But these are lessened and made more tolerable when a truly loving friend shares them with you, a friend whom you can trust to help lessen the suffering. As parents, you should be the best friends your children ever have, whether they are facing imminent death, or can anticipate living beyond your allotted lifespan. Parents too often perceive their responsibility of producing productive citizens as a heavy weight with an uncertain outcome. When a life-threatening illness appears, however, parents often find moments of joy in their responsibility.

A poem by Edgar Guest, "To All Parents," puts this into perspective.

"To All Parents," by Edgar Guest

"I'll lend you for a little time a child of mine," He said,
"For you to love while she lives and mourn for when
she's dead.
It may be six or seven years or twenty-two or three,
But will you, 'til I call her back, take care of her
for Me?
She'll bring her charms to gladden you, and shall
her stay be brief
You'll have her lovely memories as solace for your
grief."

"I cannot promise she will stay, since all from earth
return,
But there are lessons taught down there I want this child
to learn.
I've looked the wide world over in my search for
teachers true,
And from the throngs that crowd life's lanes I
have selected you.
Now will you give her all your love, nor think the
labor vain,
Nor hate Me when I come to call to take her back again?"

I fancy that I heard them say, 'Dear Lord, Thy will
be done!'
For all the joy Thy child shall bring, the risk of grief
we'll run.
We'll shelter her with tenderness, we'll love her
while we may,
And for the happiness we've known, forever grateful stay;
But shall the angels call for her much sooner than
we've planned,
We'll brave the bitter grief that comes and try to
understand."

Each of us learns in time that there is no true permanency in human experience. Everything changes, including ourselves. When groups of individuals with special problems urge us to accept this knowledge with such slogans as "Make today count" or "Today is the first day of the rest of your life," they are sharing a deeply important philosophy that we work-oriented, forward-planning Americans find difficult to heed unless our perceived

future derails temporarily.

Suddenly the future fragments, and today becomes the only day that really matters, that can be coped with, because we are reminded again that no one really can be sure of tomorrow. All any of us has, whether ill or well, is right now, and hope that there will be tomorrows. The main philosophical difference between people who do not have cancer in the family and those who do lies in perception of the future. It is more difficult for families coping with cancer to assume that the future will be gratifying and that they have some control over it.

Small children are not able to think about the future in the same way as adults. To them it is much more nebulous. It is perceived as the realization of fantasies, but not clearly defined in numbers of days or years. For them, the future is this afternoon, tomorrow, or--for babies--now. Their needs are immediate and are the only reality that exists for them.

Parents must worry about the future. Children should not have to, and they will not if the adults in their world are not overly anxious about it.

It is difficult to sustain a positive, "Let's wait and see. In the meantime, isn't this book interesting, isn't painting fun?" attitude when you are worried about the potential for pain, insufficient money, disintegrating family structure, lost jobs, and loss of your child or his future happiness.

We all long for a better than 50-50 opportunity for certainty and assume, under ordinary circumstances, that it will be available. When the perceived opportunity drops considerably below the 50-50 mark, fear begins to swell and questions arise faster than they can be answered. The most persistent personal questions are, "How much pain and uncertainty can I endure and still sustain my equanimity, to carry out my responsibilities to my sick child and to the other family members? Do I have sufficient resources without and within to carry out my responsibilities to everyone? What are my responsibilities? No one has prepared me for this. Why is this happening to us?"

It is easy for other people to review a list of "ought-to's"--You ought to sustain hope, keep up your spirits, and expect a positive outcome; you ought to trust in God to work out your destiny according to a greater plan, you ought to continue to reassure your healthy children and your spouse that they are still loved and will not be abandoned psychologically. The list is extensive. The "ought-to's" can be achieved eventually by most

people, but the trip through purgatory seems infinite at the time. You are treading water in a thick sea of unanswered questions and confusion, and until many of those questions are answered, the potential for drowning seems great. You are expected to rise to your greatest potential as a person at exactly the time when you are confronted with the possibility of the greatest loss you have yet sustained in your life. It seems too much to expect of anyone.

In comparison to confrontation with personal death or physical dismemberment, such as that faced on the battlefield, these demands for personal courage, equanimity, resourcefulness, and definition of what love truly means are overwhelming because they are needed by others as well as by yourself. It is not just a personal experience; the soul-searching has ramifications and effects that go beyond the strictly personal experience.

So, initially the role of each family member is to seek as many answers to questions as available, and reduce the natural anxiety about the unknown. People are better able to cope with a situation if they understand most of the basics of the situation. But it requires courage to seek answers that might be painful because the natural tendency for humans is to flee from pain and danger, both physical and psychological.

Your first obligation to the ill child is to be unafraid, to be the child's gladiator, and to fight the consequences of his illness with knowledge. This requires trust in the physicians selected to treat the child and a spirit of cooperation with the team of people who administer care. This is very difficult to do at times, because often the persons offering care are also responsible for some measure of discomfort which can engender fear and resentment by the child and the parents. It is extremely difficult to be philosophical and objective when a child suffers, even when you know the suffering is temporary and the end results are expected to be beneficial. If you are not convinced that good care is being given and good judgment is being used, your child will sense your doubt and will also lose confidence.

Your second responsibility to your ill child is to demonstrate confidence in the members of the health care team and to convey to the child your conviction that the team members are friends who are trying to help. If, as happens on occasion, some member of the team is abrupt or unsympathetic, it is the responsibility of the parent to act as the child's representative, since a child is unable to defend himself.

If there are other children at home and the ill child must be

hospitalized, they should be made to feel loved and a vital part of the family's struggle to help one of their members to recover. The concept of a family team trying to work together and solve serious problems should appeal to and be accepted by most children past 4 years of age. Family duties and contributions should be outlined and praised when accomplished, so that each member feels important to the total effort. No family member, however, should feel or allow himself to be "locked into" a role without relief. Each member owes it to the family, including himself, to escape at regular intervals from the unremitting demands of illness and to be able to look forward to breaks from the routine. There is no constructive justification for the attitude that because the ill child can never take a break from the illness, the family members should feel guilty if they do.

The family is the main source of emotional support and continuity for the sick child. And family members must keep themselves strong and able to cope with the myriad problems that occur during the course of the illness. Family members, particularly parents, owe it to themselves and the ill child to relinquish their stewardship once in a while and engage in activities that help them recharge their own emotional "batteries." The ill child need never fear abandonment if parents and other family members quietly assure the child of the continuity of their presence and concern. If possible, no one person should shoulder the full responsibility for continual physical presence with the ill child. The child needs to know that more than one person is available to tend to his needs.

The basic attitude that is frequently held, often without awareness by parents and other adult members of the family, is that the child's future is more significant than the present. Perhaps more than anything else, that attitude may be responsible for children's urgency to be "grown up." They sense a certain impatience with the slow passage of time through childhood.

When cancer is diagnosed and therapy is begun, parents with a future-oriented perception of their child are called upon to rethink this basic attitude, no matter what the prognosis happens to be. It is truly a major attitudinal change, and one not easily made by many people. They are not accustomed to thinking of short-term goals and much of their emotional and monetary investment in a child is stretched into the future. There is a tendency, initially, for some to respond to the need for a change in philosophy with an attitude of, "What's the use? All of the plans may be for nothing. If we cannot work toward goals, what is left?" What is left is the rest of the life allotted to that child, whatever it happens to be. And to the child, each minute

of that life is very important. Life is not to be wasted or postponed for some later time. It is to be used to the fullest as it comes.

Once the parents begin to accept this fundamental fact, their lives are inexorably changed, and they begin to concentrate on the quality of daily life, not only as they interact with their ill child but with each other, their other children, and with other people important in their lives. There is a great calming of the spirit that comes to each of us with this knowledge, and an acceptance of the beauty of each opportunity to respond positively.

If therapy is successful in extending life without suffering, it is the responsibility of all family members to invest more of themselves in the returned opportunities with renewed appreciation. If therapy is not successful and death seems inevitable, the suffering of all involved will be decreased by the conviction that the whole range of characteristics of which human beings are capable has been used to support and care for another human being. There are many experiences worse than dying while surrounded by empathetic, loving people who have done their best.

We all know that eventually most of the cancers in the world will be discovered at earlier stages and will be cured with better therapy than we now have. All of our research and presently usable knowledge supports this belief. What will not change is the family of man. Compassion will remain an innate characteristic of human beings. The drive to alleviate suffering will continue unabated unless we allow this planet to become overpopulated and must struggle with each other for scarce resources. We are not likely to allow this to happen.

There has been steady progress towards what we term a quality of existence for each member of the family of man. An essential key to continuing progress is compassion, a true emotional investment in each child who is born, and a dedication to make each minute of the life experience of each child a deeply enriching one.

We believe that the Candlelighters have mobilized this compassion in each of us to carry out the program of the conquest of cancer. Your contribution is a very great one. You have listed in your brochure many things that you can do, not the least of which is to enlarge your own education and to start preventing cancer with yourselves by heeding the many things that are known and by practicing them on a daily basis.

There are many methods for early diagnosis of cancer that are now

available. We entreat you to make early diagnosis a part of your whole effort, and urge you to help us mobilize the resources of this country. Presently there appears to be a waning legislative interest in our cancer program. One of the problems is that of ignorance. A former presidential candidate recently stated that we should just prevent cancer now that we know 80 to 90 percent of cancers are caused by environmental carcinogens. Such external forces must react on, or interact within, a genetic milieu which is probably the primary determining factor for susceptibility to malignant cell changes. If we eliminated the inhalation of tobacco smoke, we would still have some cancer of the lung. We think defining causes of cancer is a great goal. Prevention is our final goal, but, at present, there are people with maladies that must be cared for and cared for on a long-term basis.

There are nearly 400,000 people dying each year. We cannot allow that to continue. One of your greatest contributions can be encouraging the mobilization of more resources by Congress and a greater personal commitment to prevention.

One very important reminder is that approximately one-third of the total donated blood supply in the country is used by cancer patients. We could not administer successful systemic treatment for cancer without this blood component support. We urge you to enhance your consciousness of this ongoing daily need of cancer patients, which you can supply, either directly or through entreaty to your friends.

Thank you for letting us share some thoughts with you today.

V. How the Child Perceives Illness and Death

Sharon Hostler, M.D.

I think that all of us would like to maintain the fantasy that childhood is a time of happiness with no sorrow or tears. All of us here today know that some children feel more than others, but we also realize that every child faces some sorrow and loss within each stage of his own development. Each time a new task is learned, there is a loss. The task of taking your first step means that you do not get to hang onto Mommy any more.

Today we are going to address some of the issues of hospitalization, how the child perceives illness, how he conceptualizes why it happens to him, and how he perceives death. I will review for you some normal development and then use a little influence from Piaget to tell you how the child's thinking is different, how he may interpret differently than you and I would some of the things that happen to him in the process of being in the hospital and facing the death of others as well as his own.

Children do have a concept of death. Their concept of what happens to them is based on their play experiences and other aspects of regular life. They do not think of only the pain that gets our attention and is bothersome to them. They think of more, as illustrated by the child who brings a squashed caterpillar to his mommy at age 3 and says, "Put him back together again, Mom." The child at age 5 may ask of the squashed caterpillar, "Do you think he has any children?" or "Where do you think his mommy and daddy are?"

How children think about illness and how they think about themselves are evolving concepts. Viewing these issues from the child's viewpoint is very different, not only because of his size and experiences, but because of the way he thinks.

How children see depends on how their family sees the world, and that will vary depending on whether they live in Appalachia or New York City. They will be influenced by the medical profession around them, but they are going to see the world differently from members of the medical profession or the nurse who is taking care of them on the ward.

How do we know how preschool children think about things? We know by watching the way they play. We know by the stories they tell with the instruments they are given. Their drawings are another way we see how kids in the hospital are responding to stress. I have a child's drawing, for example, of the physician who was going to do surgery the next day. The drawing shows an angry face and a tongue being stuck out. This is the way the child thought the doctor was looking at him.

The child's concepts develop on the basis of his age, his family, his background, and his religious and cultural beliefs. When he enters the health system, all of these things are going to influence the way he responds. It is going to be different because of where he stands and what he has been through, how old he is, how tall he is. No matter what we do to make a nurse attractive, she is still pretty frightening. She is not someone the child knows, and he is not reassured by the colorful yellow pastel she wears that she is going to be very helpful to him in his life.

If you look around children's hospitals, you see juvenile graphics used to reassure the children. I am not sure that a small child would understand. It may reassure the staff and the parents, but not the child. There are other differences in perception. The nurse says, "Now, climb up here on the examining table," and it looks like Mt. Everest to a 2-year-old. Hematology clinic staff will say repeatedly, "It is only going to be a little stick, it is just a little needle." It is to us, but the child sees it as an enormous needle with an enormous sting. The task here is to try to predict the way a child may view these daily clinic experiences. As health professionals we try to modify and adapt the child's experiences to what he can handle but the problem remains that interpretation will differ between 2-, 4-, 6-, or 8-year-old children.

Meyer talks about the fact that we all suffer from death anxiety

or separation anxiety, supposedly related to the separation that occurs at birth. Each day we cope by denying and using other mechanisms. As a patient, the child is going to cope the way his family copes. He will follow the patterns he has known at home to adapt to illness and hospitalization. An infant is no exception. We are all aware that infants are now considered to be exciting, knowledgeable beings. Perhaps if we could just think of an infant as being motor handicapped--he does not move around very well, but he does think, he does understand, and he does respond--then we would have a firmer understanding of the way a child between birth and age 2 exists. We know, for example, that within 48 hours after birth, an infant recognizes his mother's smell as different from any other mother in the hospital. Experience at Case Western Reserve shows that an infant clearly recognizes mom by 2 or 3 weeks, and during his first year of life his whole purpose is to develop trust in this first person in his most important relationship. We expect him to build on this foundation with certain developmental milestones, like feeding himself, gaining some social skill, and being toilet trained so that he can go out and go beyond his own environment.

As soon as he learns a new skill, he is going to be able to manipulate it in a way that causes distress to the teacher. For example, he will drop his drawers in the bushes as well as in the bathroom. He is going to become more autonomous, choosing his own friends, able to play by himself, saying "no" to everything you say.

Let's think what it is like for a child who faces hospitalization from ages 0 to 2. Most hospitals worry a lot about "hospitalitis" in a preschool child. We all know there are significant changes in infants when they are hospitalized, in their eating and sleeping habits, and in their elimination patterns. When an infant is ill, his primary caretaker should be his mom or someone for whom he has developed reciprocal trust and expectations. No matter how stimulating and delightful the environment in the hospital is, no matter how hard the nursing staff tries, they are not going to respond to the cry of pain, the cry for food as quickly as Mother is going to do at home. It would behoove all of our hospital staffs to support parents during the crisis of hospitalization so that they can be the "hands-on" kind of parent so necessary during this time.

When a child is age 2, we talk about the "terrible 2's," but we are also talking about a child who really has mastered a lot of things in his external world. His most important accomplishment is the development of language, and he is now capable of

expressive thought. He has language, therefore he has internal symbols. He can think about things he has seen and experienced. And he can begin to anticipate to some extent what is going to happen when he goes through experiences.

During these first 2 years, most of us talk about death and separation as separation anxiety, and dismiss it. It is not an important issue. It is only as important as the physical and emotional bases on which that child, that organism, survives. If there is a gradual transition in caretakers for this child, it can be affected. If there is a sudden change, the child is going to respond fairly dramatically and fairly negatively during his first 2 years.

We are now going to move on to the preschool period, ages 2 to 6. Although experiences differ--a child who has been in the hospital 20 times has a much more sophisticated expectation than the child who is in for the first time--we do have a general outline of behavior for preschool children.

We know they are motor monsters. They are not hyperactive; they just like to move. They are mastering something different every day, and being able to move and do somersaults is important. We know that their relationships with their parents are changing, that little girls like their fathers a whole lot better between ages 3 and 6 than they do their mothers. Caretaking by sex makes a difference during this period.

We also know they learn reciprocal play and are able to become part of groups. Erickson describes this time as the intrusive period, where no place in the home is safe from them. This is a time of very individual problem-solving, playing doctor, finding out what really exists. This is a time of trying to find their own answers. Between the ages of 2 and 5 kids identify sexually. It is a time when conscience has evolved and there is a sense of right and wrong.

Now, I would like to talk about some of the thinking patterns. First of all, a child in this age group has no sense of time. There is only the present, and as he gets out of this period, he begins to have a little sense of what happened yesterday. The future--and I would like to emphasize that--the <u>future</u> simply does not get processed until age 5, and there is no absolute sense of time until nearly 8. The preschool child lives in the present.

A hospitalization or doctor's visit a week from now has no meaning for the child. By age 4, however, he can incorporate a

day ahead, if, for example, you say, "Tomorrow we are going to do this." Also, the preschool child is obligatorily egocentric. He truly believes he is the center of the world, and that is the only way he sees the world. You cannot say, "Think about the other kids in this room, think about the nurse." This is the only experience, the only way experience can be handled. Because of it, the child feels he has some control over what happens in his world.

Children think that a lot of their thoughts can be turned into action, and when unpleasant things happen, they assume responsibility for those unpleasant things. On the other hand, things as monumental as the sun rising and setting are tied to them because of their bedtime routine. When the sun is going down, it is time for them to go to bed. Or they think that because it is time for them to go to bed, the sun will go down.

The child comes into the clinic with those fixed ideas, and it is very hard to realize that. The hospitalized child goes through three stages--protest, despair, and denial. The first stage is protest: He does not want to be hospitalized; and he does not want to have his examination. This will last 48 hours, sometimes less. Then the child goes into what is called despair. This is when the staff believes that he is settling down and behaving well, because they are not having any trouble with him any more. But this is only temporary; when Mother comes to visit the child will start to cry again. Up until this time in life, his needs have been met by Mother when he cried.

There is also a period in hospitalization of accepting maternal substitutes; that is in the middle period. When the child is really crying and upset--for example, with a nasty procedure--then he will take what is offered by a substitute mother, who may be another mother on the floor, or a nurse. However, after about a week, the child becomes what we call incorporated within the staff. He despairs and denies the need for mothering. He is the kid who answers the telephone on the ward. He is totally denying any need for mothering.

The other aspect, especially for this group, and something that I can never get the house staff to understand, is, that it is frightening for a child to leave his mother and go into the treatment room. That pain is infinitely greater than the bone marrow pain. And the staff's anxiety about having mother in the treatment room should be weighed against the child's pain of being separated from his mom during this procedure.

Again, there is an example of a child with rheumatoid arthritis

who has become part of the staff. She is the kid at our institution who is answering the phone. She has been there too long. During this time, after 6 to 7 days, in this denial time, Mother may come to visit, and may be turned away. So will Father. The kid has no desire to go home. And without intervention, the parents begin to feel desolate. They feel the staff has assumed responsibility for the child.

When this occurs, going home can be a crisis. For 4 to 6 weeks afterwards, there are changes in the child's sleeping habits. He has problems with elimination. There is regression. There will be "acting out." Maybe 6 weeks later, a child will say, "Where were you? Where were you when I was in the hospital?" Then the anger and the distress about being deserted in the hospital comes out.

I think the central question is, "Do children mourn?" I think the Case Western Reserve group can tell us they do mourn. It takes them a long time. They cannot tolerate excessive pain. This, I think is important in dealing with siblings of the group we are talking about. What does the child, who is a preschooler, think about living and death?

We have all heard our kids say, "Who murdered the garbage?" And to a child, living may be defined as function. The boat is dead because it is no longer able to be used. Piaget has pointed out clearly that by age 2, a child can say, "The dog is alive, the high chair is dead." Those words really come into his vocabulary between age 2-1/2 and 3. He believes that anything that moves is alive. The water is alive. The car is alive. The truck is alive.

Next the child believes that anything that moves of its own volition is alive. So, the water now is still alive, but cars and trucks are not. Puppy dogs are alive. Then comes the realization that things that do not move can be alive. That comes at age 5 or 6. So when we hear kids using words, we must realize that those same words may mean very different things to them. When a child says, "Bang, bang, you are dead," he is essentially saying, "Get out of my way, you are really a bother to me." The words are not, at the time, involved with the child's conscience. What happens on our ward when someone starts using the word "death," not routinely, but occasionally, is that everyone gets very upset about such words being used with a preschooler.

Marie Nage points out there are three distinct concepts of death among children, depending on their age. She discovered this by

asking children of all ages "What do you think of death? What is death?" and having them do stories and paintings. Essentially the first group--those under age 5--described death as reversible, temporary, gradual, a punitive action. If we think about fairytales, they reinforce the reversibility of death. Snow White was kissed back to life by Prince Charming. We see this reflected in childrens' play. We see "Bang, bang, you're dead," and the best friend acts dead, but within seconds he is back up running around and playing.

Nage talks about the preschooler interviews associating death with sleep. Children attribute life functions to the dead person. You cannot sing at funerals because you will wake the dead. When you tell a child it is all over and the body in the earth does not mean anything, he will say to you, "Why do you bring flowers and put them there when a dead person cannot smell?" He may think about death being something that happens over time: he will continue to grow until he reaches the end of his coffin. He will not be dead for 4 or 5 days until X number of angels have located him. There is reversibility, a gradualness, and a temporary cessation.

Normally, the experience of a preschooler with death is his pet. I have to share a story with you. A child whose dog died had a funeral which was very therapeutic for him and all of the kids in the neighborhood. The next day, he put up a wooden cross. That sort of distressed the neighbors, but then he put a can of Kennel Ration on either arm of the cross. That was because he knew the dog was dead but thought that Kennel Ration would be the one thing his pet might need.

We talk about experience. When we separate our old people now in this society, we do not have the experience of seeing death. We make up stories sometimes that we do not believe, about the fact that grandfather, or a sister or brother has gone to live with God, and how joyful and happy it is. Yet the household is in mourning, and the child is distressed.

I think in talking about funerals a child between 5 and 6 should not be involved in that process we were just seeing. A child losing a parent, we know, goes through extensive mourning. They have not only lost the dead parent, they have lost the surviving parent who is immersed in grief. The child who loses a sibling also loses his parents if anticipatory grieving has occurred. So, it is even more devastating to the child who is really alone.

The sibling may also, because mourning occurs in peaks, say things like, "How wonderful it is that Suzy is dead. Now I have

all the room and all the toys, and you do not have to go to the hospital any more." Then the next day he may be grief-stricken, and the following day be very happy. This may be a very long period, much beyond adult mourning.

Furman's book from Case Western Reserve describes this well. The hospitalized preschool child who experiences death expects the rescue squad and the cardiac team to come and make him better. At age 6, death is separation anxiety for most children. The child who has been diagnosed and has been back and forth to a clinic where he has seen a peer group go through the same process, has seen and experienced death and knows of the absence of that person. He may in fact be closer to the adult concept of death, which we do not consider happening until age 10. He may have an awareness of his own mortality, which we do not anticipate emerging until about age 8. Again, he may have more fantasies about the equipment than the process that is taking place, but separation from parents during painful, stressful, different experiences is more devastating than anything we do to the child in the hospital.

The school-age child, 6 to 10 years old, is undergoing separation from home and acquiring a whole new peer group. He also then has different sources of information against which to check his parents since he also has access to other families.

Boys this age may be bored stiff, but they will not play with girls. They want to join clubs. They will be segregationists, and they are going to feel almost good about their abilities by the time they are 9 or 10, just to be knocked down when the puberty changes happen.

At this time the child changes from an egocentric to a sociocentric and understands that there are laws other than his wake-up time that determine when the sun rises. He can begin to see something and interpret it, not only from his own viewpoint, but as viewed through other kids' eyes, and maybe even through an artist's eyes. Religion begins to have meaning, explaining some natural phenomena, as well as the science and biology he learns in school.

A child who is ill during this time is more likely, again, using some of the magical thinking, to think he is being punished for thoughts or deeds. This is a time when kids begin to understand more about death. They go off to camp, and talk about the golden arm, the bloody hand, and all the ghosts, in an attempt to master some of the unknown.

By ages 9 and 10, ghoulish humor develops, i.e., running through the graveyard at dusk. There is some sense of mastery through the use of humor, which is an alternate of cognition in the 6 to 10 age level. Ghoulish humor is at its peak at age 9 to 10. A child facing his own death usually understands his own mortality by 8, depending upon his concrete experiences, and by 10 is able to begin to talk about the issue.

Spinetta's work indicates that the child with leukemia or other cancer knows that he is different even on an outpatient basis from the child with cystic fibrosis. He has unique concerns, but will not introduce them to us. We need to facilitate the way he begins to talk to us.

Nage and Piaget think, as do current studies examining cognitive ability, that somewhere around age 10 or 11, the child has the adult concept of death--irreversible, universal, and inevitable. There comes an increasing awareness between the ages of 8 and 10 that there is no guarantee that he will live until 70. The child of 5 will think, for example, that he may live to be 500. The child between ages 6 and 8 is likely to think he will live to be 100 or 90. The child between 8 and 10 thinks that he might have an accident or might not live beyond 10 or 11. The child begins to see his place in a larger sequence, and is probably at the most ideal point from a cognitive standpoint of accepting, understanding, and being able to deal with his own death.

During adolescence, there is a return to egocentric, magical thinking about body image, and concern about not having achieved developmental tasks. There are many of the same thinking processes, although they are not obligatory, that the preschool child has during adolescence.

VI. The Teenager and Cancer

1. Treatment

Donald B. Schwartz, M.D.

I would like to thank Grace Ann for inviting me here today and Karen and Chris de Laurier, whose child is under my care, for recommending me. I also must mention Dr. Gary Hartman. The two of us have spent a lot of time together and worked out several thoughts I would like to share with you today.

There has been progress in treatment of adolescents with cancer. You all know about it, perhaps; and if you do not know a patient or have a child with cancer, you at least read the newspapers and note that there has been a lot of improvement using the standard three modalities of chemotherapy, radiation therapy, and surgery. Patients have been known to do very well, and it is nice for us if they not only do well physically but emotionally.

Unfortunately, not all patients are destined to do well, and some must die with their disease. This is a fact that we all understand. The physician taking care of the patient, the other health professionals, the family, and the patient must cope with this problem. We must realize that in cancer treatment emotional support is the only thing that we can fall back on when the first three modalities of therapy fail. It is this emotional support that I am going to discuss this morning.

On my way here, I sat next to a 19-year-old sailor whose birthday was in March. He was maybe an early 19-year-old, healthy and on his way to Connecticut. I asked him what a parent should know

about a 16-year-old. After a long delay and a little prodding, he admitted he had not thought about it before. And I think that is probably true of a lot of us. We may not have taken the time to think about these things before, but probably a lot of what I have to say will be things you already know. One thing the 19-year-old mentioned was that he did all sorts of things his parents never even knew happened. He also said that he has tried different things. That is very common to adolescents. They are trying to express their independence and experience all sorts of new things. It is important to realize this in dealing with them.

Adolescents generally go through stages of development. In the early stage, near pubescence, they go through a rapid growth period. During this time, they tend to identify with their older peers. My 19-year-old friend on the plane said he remembers wishing that he were older, like some of his friends.

The boy also added that once he got to be older he realized it was not such a big thing. Young adolescents do not like to be judged as children. It is very hard for us to make the transition from treating them like children to initiating more adult treatment.

In the second stage, also brief, they try to experience different things and express their independence from parents and from established norms.

The final stage, the older adolescent patient, tends to be more future-oriented. The sailor I talked to had thoughts and plans that were more future-oriented. He had a desire to see more of the world in the Navy. I think what he said rings true for what you can expect from most adolescents.

To summarize, what I will cover today is divided into five main areas. The first is how to maintain a trusting relationship. The second is how to verbalize the unspoken concerns of the adolescent. The third is how to maintain privacy. The fourth is how to treat the adolescent normally when he or she has cancer; and last, how to utilize newer concepts of cancer care for the adolescent.

Trust

For the parent, I think that success in dealing with the adolescent cancer patient depends on maintaining a trusting relationship (and developing one if you are a health profes-

sional). The key to doing this is honesty. However, honesty must be tempered with hope, so that the truth is not brutal.

Unspoken Concerns

Nowadays, with so many different modalities of therapy, there are lots of people taking care of the adolescent with cancer. You all know this, but not everyone else does. It is important in dealing with a large team of people to assure good communication. This burden may fall on the parents or the patient in areas where the lines of communication are not well established. An analogous story involves my dining in a restaurant where I was served some cold potatoes. They were really cold, and turning to the waiter, I said, "These sure are cold potatoes." He said, "Oh, that's too bad." He did not do anything about it, and I did not say anything more about it. Probably I could have done better if I had improved my communication and asked him to warm the potatoes.

Similarily, an expression of concern regarding your own child might not be understood or well received. You have to communicate and make sure that what you are worried about is understood. Sometimes this burden falls on the other person. For example, I think the waiter should have asked to take the potatoes back, or if he did not know what to do, gone to find the answer. Sometimes we do not have the answers or know what to do, but at least we should be willing to look for the answer.

With an adolescent, it is nice to be consistent. As you know, consistency will decrease anxiety. However, on the other hand, it is also necessary not to be too rigid, because adolescents react strongly to rigidity.

There is a lot of emphasis on trying to get the adolescent back into school, but it is more important to assure ourselves that the appropriate therapy is being given. To my way of thinking, we must be flexible in order to suit the adolescent's needs.

Humor is very important in taking care of even a seriously ill patient. We have all tried humor in very sensitive situations, and it goes over very badly because it is just not appreciated. I do not think, however, that this means that we should not try to be humorous again sometimes, because I really think that humor helps decrease anxiety in a tense situation. If the relationship is a good one, I think it can withstand the stress of humor even if thought to be inappropriate. I remember one time recently trying to tell a joke in a really intense situation. The patient

was probably embarrassed for me, but I really do not think that occasionally misplaced humor should prevent me from trying again.

Adolescents are members of the treatment team. They are not children. They are not passive recipients of our care, and therefore we need their cooperation. To assure ourselves of that support, we must share information with them instead of keeping secrets. One of the best ways is to allow them to associate with their peers going through similar types of therapy. The adolescent, by talking to his peers, is sure to find inconsistencies in your story, unless you have been honest and forthright.

Another thing I try to avoid is special parent conferences which exclude the adolescent. Obviously, this is not always possible, and I realize that. But when I first meet a family, I tell them I would like to keep the conferences open to the patient at all times. This avoids projecting a feeling of conspiracy against the adolescent.

Verbalizing the concerns that the adolescent cannot verbalize for himself is a very important part of what we do. Adolescents are not always good at communicating, and sometimes they are not that good at getting the information straight.

Often they will have unspoken concerns because of fear. Some of these things we have to accept. We have to accept their coping mechanisms as given to us. It is very common for an adolescent, for example, to regress to a more juvenile stage at the diagnosis of cancer. I think this ought to be allowed. I think it would be nice if adults could have the luxury of regressing once in a while also and I do not find it objectionable.

We also have to avoid some of the useless pathologies like guilt. Adolescents can feel very guilty--for example, about the cost of medical care. But having discussions of the cost of medical care in the presence of adolescents makes them feel more guilty. Part of my approach is "active prevention." I will talk to the adolescent before there is a problem, and explain some of the unspoken concerns. For example, I will mention that parents often talk about finances, but adolescents should try not to let it bother them. It is not their fault they are sick, and it is their parents' obligation to manage the finances. Active prevention used to avoid guilt saves emotional energy wasted when intervention is delayed until a crisis develops. Active prevention is another key to the emotional treatment of adolescents and the development of trust.

Sometimes adolescents are not good at verbalizing their concerns

because they receive messages to avoid certain subjects. A 15-year-old girl in the hospital was talking to a friend of hers on the phone, who told her that she would be dying in 2 months. She told her mother, and her mother began to cry. That was a normal response for the mother, but the message to the adolescent was not to bring up that subject again, because it upset her mother. We all probably send messages with similar results. I am sure I probably do that, too. If you cannot handle a subject, you ought to look to a professional for some help. It is not helpful for the professional also to avoid the subject; but if there is a subject that the professional cannot handle, he or she should turn to someone else.

Of the unspoken subjects adolescents may perceive, death is probably the first one. I think it is important to recognize it as a possibility. It is probably also important in the same conversation to minimize death as appropriate to the situation, to avoid the brutality I mentioned earlier. Even a discussion of death should be tempered with realistic hope.

Another subject is friends. When cancer is diagnosed, patients notice that friends do not come to see them. If they are not warned about this beforehand (active prevention), it takes a lot more energy to reassure them later when friends do not visit. It is normal for friends not to come. They may be afraid of cancer. Sometimes they incorrectly think cancer might be contagious, or they do not know what to say. Rather than say anything, they will not visit. It is useful to warn the adolescent that even their best friends may not come to the hospital or talk to them, because friends don't know what to say. When friends do come, the adolescent should be encouraged to talk to them about the disease. Although friends may not feel comfortable, most likely that is the number one thing on their minds.

Adolescents sometimes are angry at the disease, and also at the frustration of the disease, which requires them to be dependent when they are trying to establish independence. Guilt has already been mentioned, but patients also feel they must have done something wrong to get cancer. The active preventive approach can be used to warn the patient about the problem of guilt feelings before it becomes a crisis.

Hair loss and vomiting are of concern to adolescents, but ones which they are usually able to verbalize quite well. I do not have any magical answers to these problems, and they definitely are of great concern to many of our patients. I think it is probably easier to accept the hair loss and vomiting if we as adults take a more casual attitude about it. I remember the

story of a parent measuring the hair as it was growing back. That seemed to be putting more emphasis on it than appropriate. Instead of dwelling on the hair loss, it is probably better to make plans to take care of it, like getting a new wig, and talking about what color or length. Adolescents also want to know something about the schedule of treatment--how often bone marrow aspirations are needed, how long the vomiting will continue. There is great fear and anxiety when there is no information about the length of discomfort. For example, the adolescent may understand that vomiting is necessary, but will wonder if it may not stop. We all have to remember to give them some sort of guideline for when the vomiting will stop.

Privacy

Privacy is important to adolescents. They like loud music. Some of my patients eat cold pizza for breakfast and the telephone seems to be an extension of their body rather than the wall. We all have to respect their privacy. Sometimes they need more privacy from parents. Sometimes they even want privacy from the health professionals, and this is something that we have to respect.

Normal Expectations

We also must have normal expectations for our patients, even though they are very sick. It reminds me of the story about the teenager previously denied a motorcycle who develops cancer, and then is given a motorcycle by his father. It only increased the patient's anxiety about his disease, because he realized his father would not have given him a motorcycle unless he were really ill.

So, it is important to recognize or at least assure yourselves that the concept of treating the patient as normal is useful, although it cannot be done all the time.

I do not recommend that physicians embrace the concept. The recognition that these patients have special needs is the reality of the situation for the health professional. Health professionals must be aware of adolescents' special needs, and on the other hand, parents must be encouraged not to treat the adolescents specially.

Another way adolescents behave normally is by their rejection of health professionals' recommendations. This has happened not on

just one or two occasions, but frequently to all parents. The recommendation is for repeat surgery, and they say, "No." This is normal. You have to try your best, but they do have adult bodies. It is impossible to get them to a procedure you may think is important unless they cooperate. Sometimes we fail to convince them. I guess the ultimate insult is when our treatment fails. The second insult is when they reject our recommendations. But we have to accept that as a normal process of taking care of any type of patient, especially adolescents or adults.

If you think you have good rapport with the adolescent, but he would rather talk to the evening nurse, or someone else, do not be insulted. When they have special problems, adolescents do not always look to parents; they do not always look to the physician. They may find someone with whom to share their innermost fears. We have to appreciate their desires to talk to somebody else. Nor should we prod: "Well, what did you talk about?" The fact that they are able to verbalize with somebody else is fine, and we ought to accept it although sometimes it is very difficult.

Before discussing concepts of cancer care for adolescents, I would like to mention a situation that we all should work to avoid. It happens time and time again: a parent says he did not call because he did not want to bother me. I think that the traditional role of the physician as inaccessible has to be replaced, especially for the adolescent with cancer (and probably in other situations as well). I find families run into trouble by not picking up the phone and relating a specific problem to the physician or other caregiver. The concerns are usually the greatest at night. For some reason, the dark seems to bring out some of our greatest anxieties, especially about our loved ones. So use the phone. Use it frequently when you have concerns, and then you won't have to worry about it all by yourself.

Team care is not a new concept. You are probably all familiar with it. Physicians, nurses, social workers, parents, the patient, psychologists, psychiatrists, nurses, occupational and physical therapists, school teachers, and dieticians are traditional team members. A team approach helps in taking care of any patient with cancer. First of all, it provides the patient a greater choice of confidants. It also helps diffuse the burden which parents have. If many people are taking care of one patient, all the patient's needs, not just some of them, are being satisfied. The team approach requires better communication. If a particular problem develops and has not been communicated to all team members, then further problems can arise. It is nice if physicians can have the parents as allies

to plug any of the communication loopholes that could occur.

Concepts of Care

The most important new concept we have found useful with adolescents is relaxation techniques. There are all kinds of relaxation techniques used to minimize anxiety, and they are useful in controlling pain, problems from vomiting, and generalized anxiety caused by the disease. One of the most useful relaxation techniques is hypnosis. Initially I was skeptical of hypnosis, but after using it myself, and having my colleagues use it on some of my patients, I now feel it is extremely beneficial and should be embraced by all of us who care for patients. Parents can do it. Patients can do it, but usually require the guidance of a health professional, at least in initiating the process.

Adolescent patients are ideal subjects for hypnosis. Younger patients do not cooperate, and move around a lot. So they are not satisfactory hypnotic subjects. People who do hypnosis regularly say that even though they move around a lot the young patients are still benefitting from the procedure. However, the satisfaction is less in hypnotizing a young person than it is with an adolescent. An adolescent can cooperate, where the younger patient cannot. Adolescents can concentrate, and have a high degree of motivation, especially if it will help control their vomiting or discomfort. In addition, they do not have the skepticism that maybe some of you here have about using such techniques.

School liaison is another important concept for taking care of the patient even though it is considered a luxury. Many hospitals have teachers to help patients keep up with work from school, but the school frequently does not know what has been happening with the student. The school liaison is a professional who communicates to the school information about the disease and course work accomplished.

Most of my adolescent patients have many excuses for not returning to school, and it is difficult to encourage attendance. I usually find they do better emotionally if they can get back to school quickly. If they must miss school frequently their total time out is less if you can get them back quickly after the first time out. The school liaison is a person who can also communicate to the school that the patient's disease-related anxiety may interfere with his ability to progress with his studies. A lot of schools just do not understand the depth of these anxieties.

The fear of not doing well is an excuse often given for not returning. It sounds so obvious, but the teachers or the administration must be willing to reduce or modify their goals without making the patients feel like they are receiving a gift, and without making it too difficult to re-enter.

Pain control is something we all desire. I prefer outpatient pain control, if possible. However, patients who have frequent and severe discomfort, or peaks and valleys of pain alternating with control should be hospitalized. And a technique that surprisingly is not familiar to everybody, constant infusion of the analgesic, is needed. The constant infusion allows for continual pain control and the peaks and valleys can be eliminated.

There are three other areas I do not have much time to discuss, but which are important. One is the hospice. I think it should be encouraged for those families who want to use it.

There are a lot of hospitals that have adolescent units. Admission criteria is usually based on the age of the patient--13 to 18. You all understand that the patient's emotional maturity should determine admission into a hospital adolescent unit, and not age. You may have a 13-year-old who is actually very juvenile, or you may have a 20-year-old who may just be able to relate better with the adolescent patients. You do not want to insult the 20-year-old by putting him into the adolescent unit, nor do you want to insult the 13-year-old by suggesting the children's ward. Perhaps it would be better if hospitals would rename the unit a "youth unit." I would be willing to listen to other recommendations for the name, but "youth unit" is as creative as I can get.

Sexuality I cannot talk about because of lack of information. Some of the questions are, "Will I be able to have children?" and the answer seems to be, "Maybe and maybe not." We need some more information, for example, about occurrence of infertility with chemotherapeutic agents.

So, in summary, you must realize that I sure favor patients in the adolescent group who do well both physically and emotionally, but I find there can be fulfillment sometimes with a patient who does not do well, but only if we have given them emotional support that they need.

In dealing with the adolescents, I think it is important to establish relations of trust; assess their stage of development; appreciate their inability to verbalize their unspoken concerns;

respect their privacy; try to have normal expectations; and be willing to utilize some of the newer techniques.

QUESTIONS AND ANSWERS

[Q]: How young are the subjects you use hypnosis with?

[DR. SCHWARTZ]: Unfortunately, one of the people who taught me how to do hypnosis already sensitized me by saying he has always had trouble with patients under 6. So I have the same difficulty now. However, my associate has hypnotized patients as young as 4 years of age. As I said earlier, to me they are not as satisfying to teach relaxation technique to because they move around a lot and may not be as relaxed as you would like. Yet I have been assured that they make good subjects. According to Dr. Wilbur, children aged 5 to 10 years of age were probably easier to work with in hypnosis. But my own personal experience has been that the young adolescent is an ideal subject.

[Q]: What is your feeling about sending teenagers to an oncology unit? That is another name for the youth unit.

[DR. SCHWARTZ]: Personally, it doesn't have any appeal for me. I think adolescents should be sent to an adolescent area or a youth area. In caring for all types of cancer patients, however, I feel it is better for them to associate with all sorts of other patients, and not be cast aside into an oncology unit.

This also goes for other people, social workers or nurses, taking care of adolescents with cancer. I think the burden is easier to accept if health professionals have variety in the types of patients they manage.

Personally, I feel that although it is nice to have cancer patients in one area, where the expertise is concentrated, I would like to encourage inclusion of other patients.

[Q]: Do you feel the treatment and reactions to treatment affect the child's ability to do well in school, apart from the fact that time is missed and must be made up?

[DR. SCHWARTZ]: I think the answer to the question is "yes." The patient is undergoing a lot of energy-consuming emotional anxiety that interferes with the ability to do well in lots of things, including mowing the lawn, driving the car, or other

aspects of life. I know adolescents are very resilient. But I also feel that if adolescents are sick in school and somewhat worried about the disease, their ability to do well will be affected. Often I think schools don't realize that. Just having a hospital schoolteacher is not sufficient either. But we now have a 3-year grant which allows us the luxury of having a school liaison, a schoolteacher whose sole job is to communicate between the hospital and the school, with the hope that the school will gain some appreciation of cancer in adolescent patients.

[Q]: Does the doctor share the diagnosis of cancer with a patient and family together?

[DR. SCHWARTZ]: I try to. One physician said he was coerced by the mother not to let the patient know what he had. The doctor was apologetic for this, and 2 years later sat down with the patient to tell him. I am sure the patient already knew what he had. I try to convince the family that is hesitant to allow me to start the relationship on the correct foot. I try to tell the patient from the beginning what he has, with the patient and family together.

I will ask for the permission of the patient and family at the same time. I tell them the style of my approach is to try to be honest and that I intend to have meetings with them together.

2. Pastoral Care and the Psychosocial Needs of the Teenager Facing Death

Fred W. Bender

Supposing adolescence to range between 12 and 24 years, it becomes advisable to examine the average needs of adolescents.

Offer and Sabshin (1966) suggest examining four possible meanings of normality: 1) health; 2) optimal function; 3) statistical averages for certain traits, e.g. intelligence; 4) a temporary equilibrium state, as noted in Hippocrates' balance with nature and Cannon's concept of homeostasis. Sociologically normal behavior is a reflection of cultural values and is, therefore, relative.

In terms of the psychological characteristics of adolescence, there are 10 basic considerations as outlined by Copeland (1974): 1) preoccupation with the Self (Redl); 2) preoccupation with fantasy; 3) preoccupation with philosophical abstractions, theories, and ideals (Piaget, 1969); 4) preoccupation with sexuality; 5) hedonism and/or asceticism; 6) conformism; 7) heightened sensitivity (Sklansky); 8) mood swings; 9) propensity to "act out"; 10) inhibition of behavior.

In terms of development tasks we have: 1) establishment of realistic expectations of people; 2) emergence from dependence; 3) control of ambivalent feelings; 4) development of an individual's value system and sense of identity (Erikson); etc.

Depression is a common adolescent "crisis" similar to the adult

form with sadness of mood; poor sense of self; convictions of hopelessness and helplessness; and ideas of rejection (Copeland, 1974). Academic performance is often impaired and may lead to failure and withdrawal from school (Hallan, 1970; Whitney, 1971).

As Copeland (1974) notes: Masterson (1970) suggests destructive acting out as equivalent of depression while Finch (1972) and Toolan (1969) include restlessness and overeating. Ling et al. (1970) show the importance of headache, withdrawal, and the existence of persecutory ideas. Frederick (1972) also cites fatigue in connection with adolescent depression. According to Krause (1972) suicidal behavior is the fifth leading cause of death in the 15 to 19 year age group. Guilt is also a common difficulty.

Wolf (1970), Sklansky (1969), and Robbins (1960) demonstrate the need to help the adolescent solve current reality problems along with aiding ego growth and problems of conscience. Berman (1957) sees the need to help improve adolescent-parent relationships as Erikson (1968) suggests the importance of resolving problems of identity. Holmes (1969) demonstrates the importance of limit setting for the acting-out adolescent and Josselyn (1957) suggests that deep insight is often not necessary and often too upsetting for the young patient to cope with at the moment.

For most adolescents, especially between the ages of 12 to 15, there is a movement of emotional ties away from the parents to the peer group in a seemingly self-centered and narcissistic manner. The main importance of this same-sex peer group for self-insight and situational group responses tend to fail the terminally ill adolescent. The emotional bonds are weakened by the illness and the necessary support may be absent. If the family relationship is strained, the adolescent may all too quickly and abruptly sever the ties that have existed. Adolescents often force their independence, despite a commonly felt need to enjoy their dependency, and are confronted with an absent or weak peer support group. When faced with the reality of an oncoming death the adolescent may only have his peers to call on for emotional support, and they may be of little value in this situation.

A number of adolescents become extremely negative to all parental hopes and values, usually in order to bolster a weak or inadequate self-image. Often at this time, there is a similar dissociation with religion and culture. Time and energy are commonly spent with peers in a variety of conforming, parentally independent activities. Usually this rejection bothers the adolescent and he is troubled by feelings of being uncomfortable

and guilt that he does not understand. A very difficult feeling to deal with when the adolescent learns of his terminal illness is that of punishment.

The feelings of punishment for seeking independence from God, family, establishment, etc. can easily lead to a great amount of unwarranted anger and frustration on the part of the adolescent. Parents, dealing with their own feelings of guilt, often enhance the adolescent's difficult feelings during this period. The adolescent's need for independence and difference from parents often poses challenging problems for the family situation. Parental desire to return to greater dependency or the prior relationship with the adulescent will be a source of ongoing stress initially. The adolescent easily perceives the ultimate punishment, this death sentence, as the kind that only an unforgiving parent or parental authority could mete out. He struck out for self, independence, sexuality, etc., and is feeling struck down for his presumptuousness. He often will feel that there is no one outside the crowd whom he can turn to for support and understanding.

Often these feelings make the adolescent feel ever more guilty and "sinful." So he shows bitterness and resentment towards those he really does care about. He regrets his care, his need, his dependency on them which often leads to feeling rejected, isolated, and abandoned. Younger adolescents cannot tolerate their emotion; their need for warmth, touch, love, and the other manifestations of our common human need and fraility.

As Chodoff (1959) points out, the average teenager is unbearably uncomfortable dealing with someone his or her own age who is dying. Easson (1970) claims, "The young teenager faces death, lonely and alone. He feels rejected by wrathful parents, by a resentful society, and by an unforgiving deity." Obvious physical manifestations of the illness make this process of peer relationship even more difficult.

Often adolescents will try to help others who appear weaker and thus overtax their strength. Abrams (1966) notes that he wants so much to be cared for and protected that he dreads losing control over himself. This approach-avoidance between understanding and nurturance versus the need for independence forces him to push others away. The fear of acknowledging the feelings of warmth and caring in himself, and given by others, leave the adolescent in a very difficult situation.

The terminally ill adolescent at age 14 to 16, may allow himself to be increasingly cared for by the parents as he grows weaker,

provided he feels treated respectfully. Usually there is a fascination with dying, though the adolescent does not wish to stop existing. The emotional fantasies are often the most difficult to control and to share. Who can they blame for what is happening to them? Unfortunately this is a struggle the teenager too often faces alone. The fact of dying is ultimately his alone, yet our burdens can be shared--the cross can be carried part of the way together. Death promises only defeat to the adolescent. It is difficult to use this time for deepening of personal relationships and growth seen by Kubler-Ross because so many of the relationships are transient or recently established.

The achievement by mastery of the mid-adolescent makes the on-going process of the disease more difficult to accept. Raging against the waste and feelings of futility are easy to understand. The leukemic bruise hurts and damages what the teenager was once so proud of. Self-achievement seems doomed to increasing frustration.

The older adolescent faces changes in the deeper relationships of life. At this time he realizes that he is loved by others and that he will be missed. He often finds himself hurting those he does not wish to leave. He often begins to withdraw emotionally and finds he must continue to reinvest himself emotionally in an ultimately losing proposition. Desires for or fears of pregnancy are common. Relationships of the lovers in adolescence become emotionally trying, often in haste for fulfillment. He needs truth and honesty at all times in his desire to live on in the hearts and minds of those who love him.

Sexually, the adolescent may benefit by a peer or slightly older person who, by being outside of the family/social situation, can discuss the emotional difficulties that the adolescent must face. Usually a slightly older, experienced individual is ideal though hard to find. Problems common to adolescence can be dealt with in a more productive manner. The adolescent is understandably reluctant to bring problems of masturbation, love relationships, or emotional need to the attention of parents, family, and personal friends. The sharing and real growth that can come from a relationship of this sort can be extremely comforting to the adolescent. This is an area needing a great deal of research and implementation.

Clergy and pastoral care personnel have an ideal opportunity to enhance the adolescent's response to himself and to others. There are difficulties with the individual's experience and perspective in making the opportunity available and desirable to

the adolescent. Often pastoral care personnel must overcome the natural reluctance on the part of the adolescent to share his needs with them, to take up their time, to overcome the standard stereotype they engender in the mind of the adolescent. If these prerequisites can be accomplished, these individuals can be the greatest source of internal peace and comfort not only for the adolescent but also for the family.

Now I would like you to take a moment and just imagine the responses you have received from the pastoral people at your hospitals, parishes, and synagogues. How have they really responded to you? How have they really reached out to you? How have they really touched and helped you?

One of the things that strikes me so often, especially in my own work with adolescents and their families, is that often the response is a negative one. In fact, when they are looked to for support, pastoral people often fall far short. Just for a few minutes today I would like to explore some of the reasons behind that.

Clergy in general, have a fear of being all too human, a fear of losing their perspective on the role they fill. Why? Because if they lost their perspective for a period of time with you, they might have to cry out, as you do, and say, "I don't know why it is happening. I don't understand it, either." and this is threatening to them. It is hard to admit our weaknesses, our needs, our ignorance, and it is especially hard for professionals in various areas.

One of the things we have to look at in terms of pastoral counseling is: How well have these clergy responded to you in your community, your religious community? Think for a moment. How have they? Have many reached out to you? Have many offered their time, their energy, their interest to you?

What is often noticed by parents and their families and by teenagers who are facing a life and death crisis is the "loss of presence." When they are needed, the pastoral personnel are not there. When they spare you 10 minutes, somehow you are often left with the feeling that you should be grateful that they managed to find that time. Can any of you identify with these feelings? Have any of you experienced feelings similar to this?

Another problem with pastoral counseling is that you need a humanistic response, a human, warm, caring response, not "realistic" and ritualistic thought; not absolutions; not ministrations. You need the love, the care, the depth of response

that they should be evoking in you. But it is interesting that the clergy often are not good at intimate sharing. Many of you who have gone through this process together have learned a lot about your feelings and your emotions. You shared a lot, and you realized there is a lot more you have kept inside you. Often, the clergy have not had that opportunity to develop intimate relationships with other people. Some are even afraid of it.

One of the things that is so linked with sin, with failure, with need, is fear. It is fear that holds us back. We are going to talk now about fears, especially those of the adolescent that prevent us from totally responding to our sons, daughters, or friends. A fear familiar to pastoral counselors is not being able to answer questions the adolescents might ask. This is threatening to them as well. Such a question, for example, is "Does the teenager have the right to refuse treatment, knowing in many cases that it will lead to death?" I wonder how our adolescents here feel about that. Do you have the choice? Is it yours? For many people, the answer is "yes," and this is something that can be very hard to accept.

Lastly, one of the needs of pastoral counseling is being able to listen. This means hearing not just the words, but also grasping the emotion, the effect, the need that is being communicated. I suppose we all have that same responsibility, and there are certain basic skills that many people have to work at developing--including the ability to truly listen, to truly hear what the person is saying to you.

How often in these last 5 minutes have you noticed your own thoughts drifting off to past situations, events, hopes: "Will the swimming pool be open later?" "My God, I'm hungry." Do you notice how we listen? Genuine, intuitive listening is a skill. We listen with a very small fraction of our mind, and the rest of our mind is wrapped up in ourselves, and what is going on in the future and around us.

Genuine listening is a skill that is very hard for many people to develop. Everyone has the potential, but it takes willingness to work at it, and sensitivity to the other person. There is a central theme, a famous quote you have probably all heard: "It is only in dying that you truly learn to live." I suppose when we learn to die to our needs, to our desires, to our demands, then we fully learn to live, and to listen, and to function for the other person.

What I am suggesting is for you to help clergy and pastoral team. Try to invite them to intimacy--intimacy they may enjoy, fully

appreciate, but never have had the chance and invitation to experience. I know, they are supposed to be there to respond to you and to your need, but perhaps in a fuller way you are more capable of inviting them to learn, to live, and to love in that sense.

I would like to talk a little bit about the adolescent who is acutely or terminally ill. Some of the basic needs of all adolescents are a preoccupation with themselves, with their fantasy life, with abstractions and theories; and desires--certainly a preoccupation with sexuality--often hedonism (pleasure seeking) or asceticism.

We see conformity. We see mood swings. We see a heightened sensitivity to little remarks, even though they won't show it. Often you see acting out. Sometimes their behavior and their needs are inhibited. What are their tasks? They have to emerge from their dependency. This is extremely hard for parents to allow or encourage when they are dealing with adolescents who are very ill.

In my own work with older adolescents, one of the most serious things we have to deal with is the parent wanting to keep adolescents as their children. It cannot be done. And there is that natural desire to want to protect, to save, to treasure. It is frustrating, but it cannot be done.

Adolescents are a unique group. They are often beset by feelings of inferiority, which they don't want to show for fear that they will be made to feel more inferior. They are trying to establish their own identities. They are trying to establish their own understanding of themselves, and it is difficult, because they still enjoy being dependent on you. They still enjoy the comfort that you have to offer, especially when they are acutely sick. They can keep coming back to you for that, and yet if they are going to make it on their own, they are going to have to separate themselves from you. Is that easy? No. Did anybody ever tell you adolescence was going to be easy? I don't think so.

Well, there is suffering involved here, but we have heard people talk about suffering, pain, and the possibility of death. Did you really expect, or did the adolescents expect, that life was going to be that easy? No, it is not going to be, and they are dealing with issues that are very hard for any of us to deal with, very hard--and yet they have a unique challenge presented to them.

I tend to buy into the Kubler-Ross idea of using the possibility

of death, the possibility of an acutely shortened lifespan, as a time of growth which is most essential, valuable, and even rewarding. One of the typical crises of adolescence is the existential crisis, the crisis of what is the meaning of my existence--the existential anger, the anguish. You look at these people up here today, sons and daughters of some of you, and you say, "What does their existence or nonexistence really mean?"

Many of you parents can answer that, but for an adolescent, it is a very hard question, especially when it is linked with pain and suffering. I think what they have to be able to realize, and can grow to realize, is that there is something making them uniquely valuable. Their ability to love can be brought out when you set fear aside.

It is very hard in adolescence to accept love from parents. You don't want it; and yet you want it. (Approach-avoidance conflicts, as we say in psychology.) You'd love it (the nurturance), but you can't allow them to know that you love it, because then you are vulnerable again. Then you are dependent again!

One of the things I have found in working with adolescents who are especially ill, is that they don't have time to play games. They don't have time to say, "Well, I'll give you a little of that, and you can be a little more open with me, and I will be a little nicer to you, and you can be a little nicer to me." They have a unique ability to develop and initiate but you have to get through the initial "BS" barriers, for lack of a better word, and get them to bring out their capacity for intimacy. They see an imminence of life, of love, and perhaps of death, and they do not have time to waste.

One of the things that makes their desire for independence so difficult to grant is the guilt of the parents. I have always found it difficult to understand the mother who will come in and say, "If only I had given Johnny multiple vitamins, he wouldn't have had leukemia." "If only I had done something." I guess we all feel this way at times.

In earlier childhood, when a child is faced with the possibility of death, it is often seen as the ultimate punishment coming from the parents. "No one else but my parents could have hurt me this way, punished me this way." An adolescent faced with these issues feels anger, at least from my experience. Often adolescents feel they are being punished for rebelling against God, church, family, or for seeking independence. They have been punished, and the disease is their punishment, and there is no hope of forgiveness, especially with terminal illness.

It is very hard for parents to let go at a time like this. There is a fairly famous old saying: "If you love something (or someone), let it go. If it comes back, it's yours. If it doesn't, it never was (yours)." I suppose you can apply that to the love you feel for your child.

One very important thing to realize is that it is okay to be angry with God, it is okay to be angry with your parents, it is okay to feel hurt by what is happening. After working with adolescents, I come out and I speak with some healthy students and their families. We discuss the weather, swimming, what life is like at the beach, and I find it very hard at times. That is because after experiencing the adolescent's ability for intimacy, you lose some of the ability for surface chatter and general politeness--the common things that make our society run.

I have found that many adolescents have a need to find response. They are afraid to turn to their parents. They need the support of their peers, but often their peers are not available. Much of the research suggests they need someone other than the family, that they need a slightly older peer in responding to them and allowing them to be emotional.

So, I guess if I had to emphasize three points in this section, it would be sensitivity, availability, and developing in ourselves and in the adolescent a capacity for intimacy and love. One of the things I would also like to mention is how difficult it is for men to share their emotions and feelings. I have run into this with fathers who cannot reach out to their daughters or sons. I run into it with adolescent males who cannot touch. Touching is a great ability--holding people approaching death shortly. It is very difficult for the average male to deal with his emotions, in that up-front, loving, tender, "emotional," possibly crying way.

That is partly because of the way we have been brought up and trained. It is a fear we have to understand in our husbands, understand in our children, and invite them to grow out of. It is okay to care. It is okay to cry. It is okay to be emotional, and especially to touch. So, I encourage you, when you realize your husband has difficulty in verbalizing to your ill child, that you realize the reason.

Lastly, we want to live on forever in the minds and hearts of those we love, and I think the adolescents can be called forth to use the love they have, the capacity for intimacy that they have. Then a great deal can develop. You need sensitivity. You need an openness to their concerns about sexuality. No longer can

they go in and say, "Mother, I have been so anxious, I have been masturbating every day." They just cannot do that. The adolescent cannot regress to that dependency. There is a need for someone who could be available to share their deeper emotional needs: "How romantic am I after my amputation?" "How romantic am I when my hair has fallen out?" "WHO WILL LOVE ME?" These are pressing questions. One of my own regrets is that in the short time we will be here, I will not have the ability to get to know most of the adolescents who have come here, and invite them to respond more fully, but each of you in your own environment has those opportunities.

Emotions are beautiful. Feelings are beautiful--and you have to be willing to allow them. I hope some of those comments and refections will be of some use to you.

QUESTIONS AND ANSWERS

[Q]: Mr. Bender, don't you feel a need after the teenager has died, for the priest to keep in touch with the family for 2 or more years?

[MR. BENDER]: Continuity is extremely important and also very rare. In our society in general, there is a transience or lack of permanence in anything--job, love, fashion, and marriage. I think it is very important, especially with the clergy, to have a continuous relationship. But you can have all sorts of problems like anticipatory grief when the adolescent recovers and does not die, where a clergyman or pastoral counselor can provide the follow-up with or without a review.

So, I think it is essential, but also very rare.

3. Coping: Teenage Panel Discussion

Sister Margaret Weeke, SSM—Moderator

Introductions

[JANET LANIGAN]: I am Janet Lanigan, from St. Charles, Missouri. I am 16 years old. I was diagnosed in March of 1977 as having osteogenic sarcoma. I had my right leg amputated, and received chemotherapy. I have had two recurrences and received chemotherapy and radiation. Now I am not on chemotherapy.

[DEBRA VEHLEWALD]: I am Debra Vehlewald, from St. Louis, Missouri. I am 17 years old. I was diagnosed in October of 1968 with Ewing's tumor. I have had four recurrences since then. I have taken chemotherapy and radiation, and I am now taking chemotherapy.

[JILL CHAPMAN]: Jill Chapman from St. Louis, Missouri. I am 19 years old. I was diagnosed with Hodgkin's disease in January of 1974, and since then I've had two recurrences. In the middle of July I will have been on chemotherapy for 2 years.

[EDDY KIMBALL]: I am Eddy Kimball, from Ottawa, Kansas. I am 18 years old and have Ewing's sarcoma. I am starting my fourth year, have had four recurrences, and received chemotherapy and radiation. I am on chemotherapy presently.

[KEN DANIELS]: Ken Daniels from St. Louis, Missouri. I was diagnosed with osteosarcoma in December of 1977 and have been on

chemotherapy since. I have had no recurrences.

[NICHOLAS QUIROZ]: Nicholas Quiroz from St. Louis, Missouri. I am 16 years old and was diagnosed with osteosarcoma in March of 1974. After my operation, I had chemotherapy for 2 years, until 1976. With a recurrence, I started chemotherapy again for a year. In 1977 I had another recurrence, and now I am taking chemotherapy every two weeks.

[ASHLEY BROWN]: I am Ashley Brown from Cherry Park, Canada, and am 13 years old. I was 4 when I was diagnosed as having leukemia. I have been treated for 9 years, have had three recurrences, and am taking medicine.

[VALERIE NELCAMP]: My name is Valerie Nelcamp. I am from Cincinnati, Ohio. In February of 1975, at the age of 15, I was diagnosed with osteogenic sarcoma. My treatment consisted of amputation of the diseased limb and 18 months of chemotherapy. This August, I will have been off chemotherapy for 2 years, and next February it will be 4 years since I discovered that I had cancer. I have had no recurrences, and am happy and thankful to say that today I am celebrating my nineteenth birthday.

[MALCOLM SCHORLEMER]: Hello, my name is Malcolm Schorlemer. I am from San Antonio, Texas and am 15 years old. In 1969, at age 6, I was diagnosed with acute lymphocytic leukemia. It has been almost 9 years now since I have been treated. I have had only one recurrence, and I am on partial chemotherapy right now.

[GREG WALDHOUR]: My name is Greg Waldhour, from Newport News, Virginia, and I was diagnosed in October of 1975 with acute lymphocytic leukemia. I am now 13, and I have been treated for 2 1/2 years, have had one recurrence, and am presently on medicine.

Diagnosis

[SISTER MARGARET]: For this panel presentation, I will ask the teenagers questions, and they can volunteer answers if they feel moved to do so. The first question concerns how honestly people should deal with teenagers. So, I would like to ask you how you found out about your diagnosis. Was it right away? Later in the disease? How did you feel about it, how have you handled it, and how did you like the way it was handled.

[VALERIE NELCAMP]: They did not tell me about my disease right

away. I never really suspected anything until the doctors told me on the night before my surgery. I don't know--it might have been best in one way because I did not have time to consider the problems that I would have to face. I knew that I would need to have surgery. Yet I didn't have time to suffer and agonize over it, since I found out only the night before. The doctors did tell me the truth, and I appreciate their straightforwardness. They told me that this was a life-threatening disease, and without chemotherapy and surgery, my chances were dangerously slim. I knew that I wanted to live, and that I would have to follow doctors' orders in order to gain my life. It was mainly this thought that helped me that night. So, I guess it was best that they told me when they did, in that I knew the truth. I knew what I had to do, and I did it, and there wasn't time for me to agonize and suffer over it.

[JILL CHAPMAN]: When I first found out, I just got sick. I just didn't feel well. I was really tired, and I had a lump in my neck, so they put me in the hospital. I was too tired to care. I had an operation, and after they did the biopsy on the lymph node they told me that I had Hodgkin's disease. I said, "Okay, what's that?" I wanted them to tell me what it was all about, so they explained my lymph nodes to me, and what the disease did, but they never said that I had cancer. They never said the word, and that was kind of dumb, too. I am fairly intelligent, and they said everything but "cancer"--malignant tumor and everything. But I just never caught on that it was really cancer.

I had already gone through radiation, and it was right before I had another recurrence that I realized what was happening. I was reading the encyclopedia and I saw the words, "a cancerous disease." I almost fell over. I spent a lot of nights alone in my room figuring it out, saying, "Yes, you are the one, you have cancer." It was a long time even after that, at least 6 months, before I heard a doctor or my mother or anyone say that word. I thought at the time that I was blessed with my ignorance. It got me through the process of getting well. Once I got well, it was easier for me to handle.

[EDDY KIMBALL]: I went to the hospital because I had a pain in my leg and a high fever, and I was referred to the Kansas University Medical Center. After some tests and a biopsy of my right femur, the pathology report came back. The orthopedic surgeon who had done the biopsy got my parents and myself together and told me that I did have Ewing's sarcoma, and it was cancerous. They referred me to the hematologist. The next day, a doctor who was a clinician on the team, told me about the treatments I would

have to take--the radiation, the chemotherapy. He told me of the drugs and their side effects--hair loss, nausea, acute vomiting--and I really appreciated the honesty and truthfulness I got from my doctors.

[SISTER MARGARET]: Did any of you get to meet other patients at the time of your diagnosis? Was that helpful?

[JANET LANIGAN]: When I was diagnosed, I was told. They gave me a few days just to think about it, straighten out my head and everything, and another girl who had the same disease came and talked to me. She showed me her false leg and how it worked, so I was all prepared for my operation. That really helped me a lot, seeing someone else who had gone through it, seeing how happy she was, and how her leg really didn't matter to her life. It pulled me through the operation.

[KEN DANIELS]: The night before my surgery, a kid who had undergone the same operation talked to me about it. So that helped me get over my fear. And he helped me a lot even though my friends also were there that night. I am really thankful to him.

[NICHOLAS QUIROZ]: It was the night before my operation that I found out about my disease. My mother and father told me about it. When that happened, I was only 11 years old. There was nobody around at that time who had the same disease as I did, so I kind of had to take it on my own. It was hard, of course, but after a while I met new kids that I liked. I found out that they were going through the same thing that I was going through, that I wasn't the only one. It helped me take my treatments better and easier.

[VALERIE NELCAMP]: Like Nick, I, too, was the only one at the Children's Hospital in Cincinnati at the time who had osteogenic sarcoma. So I also had to face it on my own, with the help of my parents and the Lord. I was able to cope, but since then I have talked to a number of children diagnosed after me. I really appreciate these opportunities because they tend to help me. I know now that I am not alone. And when I help others it strengthens me.

[MALCOLM SCHORLEMER]: I was 6 years old at the time of my diagnosis and there wasn't much I could understand, so my parents just waited until I could ask. At that time I was 8 years old and I still didn't fully understand. But later on I began to meet other people and patients who had leukemia. Together we would talk things over and we were friends. We would discuss

each other's diagnosis. I think being around others at times helped. But at other times I would rather have been alone and worked out my own problems.

[SISTER MARGARET]: At the time of diagnosis, was it a family affair? Was everyone included in your diagnosis?

[GREG WALDHOUR]: After I was diagnosed, I guess everyone was told. My grandparents and other relatives came up and were taking care of my sister. This was one of the last times we saw my grandfather, because he died later. And this brought us all close together before he died. That was something special to me.

[SISTER MARGARET]: Who and what kind of people did you find helpful, and why?

[ASHLEY BROWN]: The people who helped me the most were my parents. They helped me talk through my problems.

[GREG WALDHOUR]: After I was diagnosed, my doctor gave me a lot of encouragement and confidence in my treatment. I was in the fifth grade when I was diagnosed. My teacher had the class write letters to give me encouragement to go on with my therapy.

[JANET LANIGAN]: The people who were most helpful to me were the pastor and my parents. They treated me as an adult, like I could handle it, and they were honest with me. Other people who have themselves suffered have helped me out a lot also. Knowing that other people have gone through the same thing was most helpful to me.

[JILL CHAPMAN]: It was a while before I got to know Sister Margaret, but she helped a lot, simply because she never gave me any advice. A lot of people did that.

The people who really helped the most were the sincere ones, but mainly those who would just listen. I found out after a while that that is sometimes not very easy to do either. Sister Margaret did that for me, and my mom says that she has cancer as much as I do. And the really closer but older friends I have, didn't have to talk about it. We just knew it was there, and that it wasn't that important to how our friendship worked out. It wasn't a big deal. It wasn't a little deal. It was just there. It helped.

[VALERIE NELCAMP]: One thing that really helped me, the one quality that I appreciated most in people, especially in my peers at school, was a sincere friendliness. I appreciated it when

people treated me just like "one of the gang." These were kids who knew I had lost my leg from cancer but still accepted me for who I was and what I was. They looked to the inside, and not so much to the outward appearance. They accepted me and supported me, believed in me, and treated me like anyone else.

Changes and Difficulties

[SISTER MARGARET]: You must have run into some problems when people did not treat you normally. Did that make life more difficult for you?

[MALCOLM SCHORLEMER]: I remember when several people would come up to me and they would wait on me hand and foot. They would give me great pity, and I really didn't like that. I like to be treated, like Valerie said, as "one of the gang," because I am just another person with maybe one or two different qualities. And I think all people should be treated equal to one another.

[DEBRA VEHLEWALD]: My friends really changed toward me a lot. I was pretty young, and I had a lot of problems when I first got cancer. I lost my hair, and I had many problems with my friends and with others. They couldn't understand. Nobody would ever come up to me and say, "Why did you lose your hair, why are you always sick?" I couldn't ever do anything on weekends. I wore a wig all the time, and the kids would try to pull it off. They would make fun of me. I couldn't really live like all of my other friends. They could go out and do things they wanted to do, and I always had to stay home and be sick. It was just really hard when I was younger.

But now people walk up to me. They talk to me. They come out and say stuff.

[SISTER MARGARET]: How did you handle it?

[DEBRA VEHLEWALD]: Well, when I was younger, it upset me. I just went home and forgot about it, or went home and sat down and cried. I could never say, "Well, hey, I have cancer, and I can't help it." I would sit and say, "Well, it is something I have got to live with." I never--which was my mistake--came out and said, "Well, I have a problem, quit making fun of me." I put up with it, and just let people run me around, but now I say my piece.

[SISTER MARGARET]: What were some of the greatest difficulties you had to deal with?

[VALERIE NELCAMP]: I think the greatest difficulty I had to face with my treatments was probably the chemotherapy. It made me deathly sick, and I never had an IV or a vein for the IV's. There was always so much pain and sickness surrounding the chemotherapy that I sort of became paranoid about going to the hospital, and I think a lot of people do develop these psychological problems. I know that whenever I would enter the clinic door, I would immediately become nervous and nauseated. Even before they gave me the medicine, I would be sick to my stomach. Adriamycin was red in color, and it got to the point where the sight of anything red, be it jello or creme soda, would make me sick immediately. Even though it is all in your head, and it is not the medicine that has made you ill, it is a real sickness. And I think a lot of teenagers have to face these psychological problems surrounding the medicine.

[SISTER MARGARET]: Did any of you go through periods where you just felt like you didn't want to go on with the medicines, that you just wanted to stop and give it all up? And when you did feel like that, what helped you to get over it?

[NICHOLAS QUIROZ]: I wanted to quit many times, because I got tired of chemotherapy, IV's, pills, and shots. But I would talk it over with my mother and various other people, and they encouraged me to go on with it. They said if I did not take this treatment, and if the disease struck again, who knows, perhaps they wouldn't be able to do anything for me then.

So, I stuck with it, and I am still sticking with it. Every time I think about quitting, I think about the recurrence, and that it might reach a point where they couldn't do anything about it. So, I would tell others, too, to stick with it. It is hard, but you have just got to bear with it if you want to live.

[JILL CHAPMAN]: I have a comment in reference to the chemotherapy. The chemotherapy was the hardest for me, too. When I was sick, my only objective was to get well. But chemotherapy was a different story, because I was well, and they were making me sick. I had two courses, two sets of it. I don't know exactly what the term is for them, but the first one I went through made me worse.

I would go into the clinic--and the clinic was a sight then. There was a waiting room with hard folding chairs which are really hard to sit on when you've lost a lot of weight. By that time, like Valerie said, I would get sick, not physically sick, but just sickly. And it only made my weekends worse. I just never got any better.

They gave me a blood transfusion and stopped my treatments early. That was New Year's Eve, and I went to a party that night. It was fun, but after that I went to the clinic for about 7 months. I had another recurrence that lasted 6 months before they did anything, because there was nothing to be done. We were not sure what it was. Then I started with the chemotherapy again, and at least psychologically, I was starting right where I had left off. I didn't do any better, I just got worse. At one point, my veins were fibrosed so badly that it was hard for them to find a vein that was usable. So they stuck me quite a few times. My arms were hurting, and in one vein I had a hole that bled and left a bubble. I had another bubble in my other arm from the liquid. I was really upset, and got physically sick before anything really even happened, other than just getting stuck. I guess because I got sick and vomited, Sister Margaret said, "Well, Jill, don't you think you ought to think about why you get sick beforehand?" Being reasonably intelligent, I said, "Okay, there's got to be a reason." I knew there was. I just had never done anything about it. We went home, and my mom pestered me for a week at least, constantly saying, "You ought to think about it." Once I started thinking about it, things began to improve, and this is kind of the success story of the bad part.

Chemotherapy is bad news, but it doesn't have to be that bad. I have never had any hypnosis, just will power, I guess. I don't know what it was, but I worked on figuring out what was really going on, and not what I thought was going on. That way I didn't get sick as much. I just decided not to get sick. So I would go home, maybe get sick once, and after that I'd have dinner, and be well for the rest of the weekend. Of course, it was a gradual process; it didn't happen just in one treatment. By the end of my treatments I would go to the hospital and get nervous, but not get sick before or after the treatment. Then I was finished. So at least I know it is possible.

[EDDY KIMBALL]: When I first started my chemotherapy treatments, I was taking Cytoxan, which really makes you deathly sick, you might say. I would get the treatment on Friday mornings and I would be sick until Sunday afternoon, I mean, nonstop vomiting. It was pretty bad. I would get dehydrated sometimes. It just was no fun at all. I had no weekend at all, and was in school the rest of the time.

Eventually, I started getting sick and nauseated before even taking the medicine, even when I walked in the door. I could taste the medicine when I got the IV, and I would start throwing up while I was getting it because it tasted so awful. Well, a psychologist on our team, Dr. Lansky, suggested I talk to another

psychologist, Dr. Cooper, who suggested self-hypnosis and taught me how to do it. It worked some of the time at first, and then I guess eventually I stopped throwing up so much.

[MALCOLM SCHORLEMER]: The treatments and the effects of the treatment are enough to make anyone want to give up. It had been a long time since I had a spinal tap. Really it had been years. But they had done a spinal tap on me just before the weekend I was supposed to go down to my grandmother's. It was a pretty long drive, and I had to sit up all the way, which was a real mistake, because I couldn't straighten out afterwards, and I was carried all around. It was really painful.

Before that, I used to get bone marrows about once every month, and after a while so much calcium had deposited on my hip where they stuck the needle that they couldn't get the needle out. I remember the doctor had to use five or six needles because they kept bending. Sometimes it can be physically painful, and really, most of the time it is mentally painful.

[SISTER MARGARET]: We have spent a lot of time talking about the effect cancer has had on your life. How about life attitudes? Would you like to go into that now?

[VALERIE NELCAMP]: I have learned a great deal from my experience with cancer. I have really come to realize that life is something very precious. It is a gift to be held onto and to be treasured. Earlier, we were talking about giving up and I think that that is the worst thing a teenager or any person can do when he discovers he has cancer, because if a person sets his mind only to defeat, he will probably end up in defeat.

When you are experiencing treatments, and when you are going through cancer, it seems like going through a dark, endless tunnel, filled with all kinds of pain and misery and fear. But I now realize that there is a light at the end of that tunnel, and it is worth taking this long journey in order to gain your life.

Also, I see more good in life than I ever used to. I am thankful for the future that God has given me, and I like to get as much good as I can out of life. I believe that we should live one day at a time, but plan like we are going to be here forever.

[SISTER MARGARET]: Greg, you had something to say about that when you were talking to Channel 4 a while ago. Do you remember what you said?

[GREG WALDHOUR]: The man on Channel 4 was asking me if we had a

motto or something for all the kids that have cancer. As Valerie just said, I always think of, "You live your life one day at a time."

[EDDY KIMBALL]: One of my doctors who had never said anything like this before told me to thank God for today, and ask Him to make tomorrow an even better one. That is something I try to do. It was a time when I was very depressed, about 6 weeks ago, when things weren't going too well. I lost a lot of weight, and eventually gained it back fortunately.

[KEN DANIELS]: After my diagnosis, I went home and was on crutches for a while. It was during the winter, so I could not roam around much, but I tried to do as much as I could and my friends came over a lot. Then we had a lot of snow days off so they could help me. When I got a prosthesis, I just thought every day that I would be able to walk around again, and try to do different things, like my doctor said.

So when I got my artificial limb, I learned how to walk, and how to conduct myself and I have done quite well since. I still do a lot of the same things as before. I play basketball, baseball, and lately, golf. One of my coaches at school asked me to kick field goals this year in football, so I am going to try to do that. And I have been doing things I like to do, which has really helped me. When I was in the hospital for my surgery, I really thought about this. I had never heard or known anything about prostheses or artificial legs. I thought I would be in a wheelchair until my doctor told me about my better option.

[JILL CHAPMAN]: I had never been sick before, so it was kind of a shock. It just turned my whole world upside-down. I had to get a quickie course in growing up. It was something you just had to do, and it taught me, like Valerie said, a lot about life.

We were talking about this earlier in our group from St. Louis. When you say the word "cancer" people who aren't well-informed think "death sentence." They don't think there is very much chance. And sometimes when you talk about cancer you also talk about death. It can be the same word sometimes, but I don't have that kind of feeling about it at all. Of course I do think about death, about cancer being life-threatening. But I also thought about life. I learned how to LIVE--not just exist. A lot of people live, but they don't live to their potential. I don't live to my potential, and that is really what being sick taught me, that we really take for granted what we have. To live, to really live, takes work. I guess that's what I learned, and that is the most valuable lesson anyone can learn.

[SISTER MARGARET]: Janet had a different kind of experience. She knows the difference between losing a leg and losing her hair, and I would like her to tell the audience about it.

[JANET LANIGAN]: The result of chemotherapy was that I lost my hair. When I lost my leg, I knew there was no alternative. I just faced it. But when I thought about my hair coming out, too, I thought, no way would God take away my leg first and then take away my hair. I just put it out of my mind. I knew it wasn't going to happen to me.

My hair came out, and I made it really hard on myself by just holding onto the hope. I was praying for a miracle when I should have just been praying for sustenance. Losing my hair was much harder than losing my leg.

[NICHOLAS QUIROZ]: It sure affected my life. I have one arm now and I will have to live with that forever. I have got to do things differently so I won't be kept back from being what I want to be when I grow up.

[EDDY KIMBALL]: It has affected my life this way: I have always been interested in science, and had hoped to have some kind of career in science. Once, when I was depressed, I got a letter in the mail from Westinghouse. It asked if I wanted to enter a science contest. I was so depressed; I felt there was no way I could ever win that or anything. As it turned out, I didn't win an award, but I still benefitted. With the help of one of my doctors, I did a project on the clinical effects of chemotherapy on pediatric hematology patients. I spent about 6 months interviewing different kids from the Kansas University Medical Center. I wrote a paper on it, and as a result, I hope to do some kind of research in biochemistry and it may or may not be on cancer.

Feelings about Parents

[SISTER MARGARET]: Were there times when you hated your parents for making you take treatments?

[JILL CHAPMAN]: No, I didn't hate my parents. No, I didn't blame my parents for that at all. I blamed myself for getting sick. I felt guilty. I hated myself for making my parents go through all the hassle, but mostly the financial deal; the bills bothered me. So my parents were more innocent than not, and I was the Bad Guy.

[MALCOLM SCHORLEMER]: I guess in the back of my mind I hated them for making me go through the pain but I also knew it was for my own good.

[VALERIE NELCAMP]: Yes, I often resented my parents for making me take the treatments. I felt angry because I was the one who had to suffer. I alone had to face the pain, sickness, and misery of the IV's and chemotherapy. My parents couldn't possibly understand. Why then, should they be able to exercise such control over my fate? Had I no say at all in the matter? Of course, even while these thoughts were lurking in my mind, I knew that my parents were right. I knew that they loved me and that they were doing everything within their power to help me finally overcome cancer. I had enough sense to realize that the chemotherapy would give me the best chance of gaining a new hold on my life. I honestly believe that I would have gone on with the treatments even if the decision had been solely turned over to me. I guess my parents were in reality a scapegoat for my own bitterness and frustrations.

[NICHOLAS QUIROZ]: I take treatments, but I didn't hate my parents for it, because my parents weren't making me take them. They said I could quit any time I wanted. But when I would think about quitting, I would think about it for a while. One day I asked my doctor what would happen if I quit, and he said, "Well, you might come back again, and we might not be able to do anything for you." And then he said that I would die, so I thought about that. Since then I've almost quit about three or four times, but every time I would think about it I would remember what the doctor said. So I only have about a year to go with chemotherapy. My doctor said that from this July to next July, if there is no recurrence, then I'll be finished with chemotherapy.

[JANET LANIGAN]: I don't blame anything on my parents. From the very start, they gave me the choice whether to take chemotherapy or not. I don't know what would have happened if I would have said no, but I always felt like it was my choice. They never pushed me into anything.

Family Visits to the Hospital

[SISTER MARGARET]: When you were in the hospital, did your parents or sister spend a lot of time there? Would you have liked more or less time?

[JILL CHAPMAN]: I think my parents met a happy medium. At first, they were both staying all day. They never spent the night like some parents do, but they asked if I wanted them to stay. I think my mom would have liked to spend the night, but I said, "No, don't spend the night--go on home." I would have liked them there, too, but I felt too guilty. But as time went on, my parents settled down more, and took turns coming to see me. I felt better about that. I kind of wished my brother and sister had been there more. When they came they were given candy and stuff like that. And perhaps if they'd been there with me, without all the bribery or whatever, they would have dealt better with my sickness.

[SISTER MARGARET]: How do you think your brothers and sisters dealt with your illness?

[JILL CHAPMAN]: They really resented it, because they were at home, shuffled back and forth between relatives and they didn't really understand what was going on. I really didn't know how to deal with them because this was a big sibling rivalry deal. Here I was demanding all my parents' attention, and my brother and sister really had a hard time with that--especially my sister. But she understands that I've been sick, and she has dealt with it in some way. I've talked to her a little about it.

[SISTER MARGARET]: Did your parents ever have trouble letting you have time to yourself when you were hospitalized? If so, would you welcome a staff person asking to see you especially? Or would you rather not have had time alone?

[JILL CHAPMAN]: No, my parents had a good time schedule. I had time to myself, but I wasn't by myself all the time. I needed my parents' support when I had tests and stuff. I really needed them there. And they were there when I needed them. And I did go through some of the tests by myself, and that was okay. You can probably tell by the way I talk that I'm really satisfied with how my parents reacted to the problem.

[SISTER MARGARET]: When you were in the hospital, did your parents or brothers or sister spend a lot of time there?

[NICHOLAS QUIROZ]: In the beginning, yes, they did, because I had one sister and one brother at home. After I had my arm amputated, the whole family was here. My brother flew in from California with his wife, and my other brother, who was getting out of the Army very soon, came home. So my whole family was there, plus other relatives. My family spent a lot of time with me.

[SISTER MARGARET]: Would you have liked more or less time?

[NICHOLAS QUIROZ]: I was satisfied with the time they spent with me. After a while, you get tired of visitors, and want to watch TV or go listen to the radio, or go in the Teen Lounge where you play games and other things, or just go to sleep. The time they spent with me was fine, so it didn't matter if they spent more time or less time.

[SISTER MARGARET]: How do you think your brothers and sister dealt with your illness?

[NICHOLAS QUIROZ]: When they first heard about it, they were shocked. They were sorry to hear about it, but they didn't know what to do. They just had to bear with it and spend a lot of time with my parents. I don't know how they dealt with it, really.

[SISTER MARGARET]: How did you deal with them?

[NICHOLAS QUIROZ]: Well, I just told them, "Don't feel sorry for me. I don't want you to do anything for me. I need to learn to do different stuff in different ways now. But I'm still Nicky, the same person that I was before, but now it's just with one arm. And I'll do stuff for myself--I don't need any help unless I ask for it." And up to now they don't give me any help unless I ask for it.

[SISTER MARGARET]: Did your parents ever have trouble letting you have time for yourself when you were hospitalized?

[NICHOLAS QUIROZ]: Not Mom, because she smokes, and most of the time she's out in the waiting room smoking a cigarette, crocheting, or talking to somebody. But when my brothers and my dad come, they just lie on the bed and watch TV. I just run off somewhere, or I spend some time with them and then I run off. No, I don't have trouble finding time for myself.

Also, my parents were my confidants in the beginning. But now it's friends my age, because I explain to them what I talk about, and they pretty well know what I talk about now. In the beginning, I had to explain what was going on to them. Now when I talk about it, they know what's going on. They understand me, and don't mind if I talk about it. At least, I don't think they do.

[GREG WALDHOUR]: My sister had it easy since she had the company of my dad and grandparents the whole time.

[MALCOLM SCHORELEMER]: I suppose my brothers let me get away with a lot. All in all they spoiled me and I let them.

[SISTER MARGARET]: How do you deal with your parents' emotions, their hang-ups, their inability to cope?

[GREG WALDHOUR]: I don't think they have hang-ups anymore but they sure had to deal with a lot of bad emotions.

[VALERIE NELCAMP]: I don't believe I consciously dealt with my parents' emotions, hang-ups, or inability to cope. Whenever they had problems dealing with my illness, we would simply discuss them and attempt to gain insight into one another's feelings.

[JILL CHAPMAN]: Well, basically, I completely rebelled. I didn't rebel against their emotions but more against their inability to cope. In the very beginning, they were not able to cope. They cope well now; all of us do. They cope, I like to think, because I made them and I made myself cope. I tend to be a perfectionist, and I insisted on some kind of coping on our parts. I think I've always said that--I think the patients determine the feeling. When I tell people that I have cancer, I don't say (lowering voice) "I have CANCER"; I say "Hey, I've got cancer, you know." And it's not to be taken lightly, but it's not death either. People will react to how you insist they react. And that's how my parents and I worked it out, too.

[SISTER MARGARET]: What did your parents do or didn't do to help you deal with your illness and communicate your feelings?

[JILL CHAPMAN]: They were very open; they let me be me. They never, never inhibited me. They never stopped me from being what I was. I appreciate that. They helped me grow as a person. I'm Jill Chapman. I am what I am, and they never tried to stop that. If I was mad, thinking "How can I be sick? I don't have to be sick. I want to be normal," they let me feel that way.

[SISTER MARGARET]: Dr. Schwartz talked about confidants. Were they mostly your own age or parents or adults outside your family?

[JILL CHAPMAN]: They were not mostly my own age. There were very few people my age who would listen to me. They couldn't listen openly and that's what I needed. I didn't need anyone to make judgments. I was confused enough about it without confusing someone else my age. I had a best friend, and I'm sure she grew a lot from wondering if I would die. If she were in the same

position, I'd have to think of that, too. But mostly my confidants were older. My mother and I, every once in a while had a relationship that was really special, but it was largely nonverbal. Verbally, adults were my biggest source. My grandma especially, because I confided in her a lot. I told her what I was thinking. I might have been talking about church or something, but I knew she was listening to what I had to say. Whether it was just because I was her grandchild and she was consoling me didn't matter. I knew she was really listening, and that's what counted. Later on it was other adults. When I was in the hospital, I didn't really confide a lot in adults, but when I got better, I told more to adults who I thought would understand. I had a Sunday school teacher once who was real helpful, and the lady was great at listening. Sister Margaret is good at listening, and now and then, when I was taking treatments, I would air my feelings to Sister Margaret.

[VALERIE NELCAMP]: My confidants were mostly my parents and in particular, my mother. Because she was with me almost constantly during the 18 months of therapy, I felt that she truly understood and could help. Both of my parents were a never-tiring source of support and encouragement. They love me, and who better to turn to in a time of need? Since I was her only patient I could go to sleep without fear that my IV would run out, back up, or infiltrate unnoticed. And I knew I could depend on Mom to make sure I got the right medications at the right times. But most of all, I'm grateful to her because she provided me with understanding and companionship. She was my hospital ally, always ready with support and encouragement.

My father and brother, however, didn't spend as much time with me in the hospital. The drugs made me deathly sick and I honestly didn't care for company when I was in that condition. Dad and Greg would usually come to visit when I started to feel better and I appreciated that much more.

[SISTER MARGARET]: Again, when you were in the hospital, did your parents or brothers or sisters spend a lot of time there? Would you have liked more or less time?

[MALCOLM SCHORLEMER]: My mother was there an awful lot and I wish she wasn't there as much so I could be more independent.

[GREG WALDHOUR]: My mother spent most of the time with me.

[VALERIE NELCAMP]: I truly don't know how to answer this question because my brother is not a very open or talkative person. I know that he did have some emotional problems as a result of my

illness, but my parents were able to deal with them. Greg just never seemed to want to talk to me in depth about his thoughts and emotions. However, when he did, I was always willing to listen and sincerely discuss my feeling and the various aspects of my disease. I do believe that my brother and I have a mutual understanding that is not always expressed verbally.

The Professionals Dealing with Us

[SISTER MARGARET]: On outpatient and clinic visits, what can the nurse do to help make the procedures and IV's less painful? What do nurses do that you wish they would not?

[MALCOLM SCHORLEMER]: Well, for one thing, it seems like they refrigerate their hands. And all the antiseptics they put on your skin. I don't know if they do this anywhere else, but the registered nurses in San Antonio sometimes give the treatments for the doctors. I always want the doctors or nurses to tell me if there's going to be pain, because I always want to prepare myself for a shock.

[SISTER MARGARET]: During the course of your illness and treatment, is there anything you wish someone had done or said but didn't? Who? What?

[JILL CHAPMAN]: I didn't know at first that I had cancer. In a lot of ways that's an advantage; in some ways, it was hard. When I found out it was cancer, I was by myself. My parents didn't know that I had found out. I'm sure they probably thought, "She really doesn't know what's wrong with her," but I did know later on, and I dealt with it myself. It was easier for me to deal with it that way. If I had known right away that I had cancer, the process would have been longer. When I was by myself, I could be depressed. I could say, "There goes my positive attitude," and work back up to it before confronting anybody else. There are probably things that people should have done or said, but things worked out for the best, and I'm not really complaining.

[MALCOLM SCHORLEMER]: I would like a staff person (really anyone different) to talk to.

[VALERIE NELCAMP]: During the course of my illness and treatment I wish that the doctors had been more optimistic and less matter-of-fact. But mostly I wish that my peers at school had sincerely accepted me.

[SISTER MARGARET]: What things do your doctors do that are most helpful to your understanding of what is happening to you?

[JILL CHAPMAN]: When they answer my questions--oh, the dears! If I ask them a question and they answer me in language that I understand without too much vague stuff. That's the best way I can understand what I'm going through.

[GREG WALDHOUR]: He (the doctor) explains everything to me.

[MALCOLM SCHORLEMER]: I never like surprises and I have always wanted the doctors and/or nurses to explain treatment and to tell me what pain and side effects to expect.

[VALERIE NELCAMP]: The main thing my doctors did that was most helpful was their explanation of the medicines. They helped me to see how the drugs fought the cancer cells and prevented a metastasis of the disease.

[SISTER MARGARET]: What are the obstacles to understanding posed by the professionals?

[JILL CHAPMAN]: When they don't answer your questions. I know some of the answers have to be vague. But other times you really need someone to come right out and say what the problem is. And when they do, you're all right; when they don't, you can't understand.

[MALCOLM SCHORLEMER]: At times they act as if they are disinterested. I think doctors should always listen and be interested in the patient's problems.

[VALERIE NELCAMP]: One great obstacle to understanding posed by the professionals is their total matter-of-factness or "get the job done" attitude toward the patient. I think it is important for a doctor to be compassionate and somewhat attuned to the emotional problems of the cancer victim.

The Use of Marijuana

[SISTER MARGARET]: Did anyone on the panel take marijuana to lessen side effects?

[NICHOLAS QUIROZ]: As far as I know, nobody took marijuana. I didn't, and if it lessened side effects, I don't know. But later on they might let cancer patients fight chemotherapy by smoking

marijuana. I'm not taking it now. I don't know if I ever will in the next year or so, but I might.

[VALERIE NELCAMP]: I never tried marijuana to help lessen the side effects of the drugs.

[JILL CHAPMAN]: I don't know if anyone else has. I haven't, ever since I've been on treatment. It's not that I'm against it. Marijuana can help lessen side effects, but the human mind can also eliminate side effects. And that is the road to take. I believe in people, and I don't believe in an artificial stimulant. I think we can do it ourselves. I wish people had the strength to do it themselves instead of relying on something like that.

The Right to Refuse Treatment

[SISTER MARGARET]: Did anyone (member of the clergy, physician, or parents) talk to you about the right to refuse treatment?

[MALCOLM SCHORLEMER]: No, and I don't think I would refuse treatment.

[VALERIE NELCAMP]: No, the right to refuse treatment was not discussed with me.

[JILL CHAPMAN]: Whenever this has come up, it's been, "You do have the right to refuse treatment." But I have never personally considered it a choice. It may be my right, but it's nothing I would choose to do. The way I feel presently may change later. I'd have to be pretty set to tell my parents I was going to refuse treatment. My clergy never got involved with that kind of thing, and my doctor would tell me I was crazy, probably.

Impact of Cancer on Maturity and Behavior

[SISTER MARGARET]: In your initial diagnosis, it seems to me that teenagers are thrust into adulthood. It seems to me there must be a lot of anger. Can you comment?

[JILL CHAPMAN]: Yes, there is a lot of anger. I was very resentful because all my peers could be concerned about the latest fad, boyfriend, and all that stuff, and I had to think about important things like death and sickness. When I first realized

the difference between me and my peers, I really resented it. I felt I had been cheated out of a carefree time that I should have had. Really, in a lot of ways, their life wasn't so carefree, but it was more than mine. Later on, when I began to put things together, I realized the immense advantage I had over them, because here I was (I was still a kid--but I was also closer to adulthood than they), so in a sense I had the best of both worlds--something that they probably will never experience.

[NICHOLAS QUIROZ]: I'm not angry that I'm thrust into adulthood, because we have to grow up sometime. So I think now is as good a time as any, because you have to deal with life. It took a lot out of me when I lost my arm. You are really a kid, but you can't be a kid.

[MALCOLM SCHORLEMER]: I kind of like the feeling of being mature at such a young age.

[VALERIE NELCAMP]: Teenagers are definitely thrust into adulthood when they first learn of their diagnosis. There's no way around it! The life-or-death decisions that one must face when he discovers he has cancer cannot be made by a child. The teenager has no choice but to meet reality head on. This is especially painful and difficult since he truly understands that reality. A child could possibly be shielded from the facts, but not a teenager. He knows what death is. He's aware of its finality. At a very early age, the teenager must find the strength, courage, and inner peace he needs to make the decision to do everything in his power to fight cancer and then see it through. Also, whereas a child is "today-oriented," the teenager must become "future-oriented." He must be able to look ahead and realize that his sufferings now will insure his future.

However, the teenager does feel a great deal of anger at being forced into this position. I can remember bitterly resenting the fact that, while I had to cope with a world of pain, sickness, and death, others my age were enjoying that happy carefree life of the young. In contrast, I believe that the teenager often feels angry because after his diagnosis, he is suddenly thrust back in the childhood role of dependence on parents, doctors, and others at a time when he is just beginning to discover life for himself. With so many decisions being made by these people, the teenager may sometimes feel as if he has lost all control over his own destiny and has been robbed of the power to make his own choice.

[SISTER MARGARET]: How has your illness and/or your experience changed your life?

[JILL CHAPMAN]: It changed my life a lot, turned everything upside down, and made me rearrange it all and turn it back rightside up. I was destined to be a person, but because I've had this experience, I'm not only a person, but I am a living being. How's that for drama? It's changed my life because it made me really live. It made me appreciate people for what they are and realize something that I may not have realized before--how much people have in themselves that they don't always know about.

[MALCOLM SCHORLEMER]: I try to live each day to the fullest.

[GREG WALDHOUR]: It has brought me a lot closer to God.

[VALERIE NELCAMP]: I know that my experience has strengthened my philosophy about life. I am not as frivolous or careless with it as I might otherwise have been. I love life and I'm excited and thankful for the future God has given me. I recently read that the number one cause of death among teenagers is suicide. After the fight I put up for my life, I find this totally incomprehensible.

Attitudes Towards Death and Dying

[SISTER MARGARET]: Do you think about dying?

[JILL CHAPMAN]: I do think about dying when it's not close or when I'm not worried about it. If I'm sick, I wouldn't dare think of dying. Mostly when I think about dying, it's what's after the dying that I'm more concerned with. Dying is okay because I believe that dying only leads to a better existence. Because I was raised Baptist, I've always believed in heaven, and right now my big definition of heaven is a better existence. It works out better for me to think of it that way rather than of mansions and streets of gold. And because I think of it as a better existence, there's less fear in it. When I'm sick, I always say I "put it in neutral and coast through." But once I realize that I am not going to pull out of this one, then I know I'll have to die. From that point until the point when I do die, I want to achieve some kind of acceptance of it. I can't accept dying before then, because that would be self-defeating.

[SISTER MARGARET]: What if they came in and said they didn't think there was anything else they could do for you? At that point, do you think you would immediately accept that and go on? Or do you think you would probably fight that for a while?

[JILL CHAPMAN]: Oh, yeah. I'd fight it for as long as I could. And then, I'd say, "Well, you've been wrong before," and hope for the best. And then if it didn't work out, I can't say how I'll feel. I know I'll be scared out of my pants to die, but as long as I can get any kind of acceptance about it, I'll be okay. I know that because I've done that before. As long as I can accept some idea of it, like a better existence--then I'll do all right.

[SISTER MARGARET]: If you thought you were dying, would you ask somebody if you were? If the doctors thought that you were, would you want them to come to you and say, "Is there anything else we could do for you?"

[JILL CHAPMAN]: I would only want a doctor to say that to me if he gave me some sense of hope.

[SISTER MARGARET]: But if the only sense of hope he could give you was the fact that they would try to keep you comfortable, would that be enough hope?

[JILL CHAPMAN]: No, I don't think so, but that's a hard question. A lot would depend on how I felt about it, too. But I wouldn't just want to be left with nothing.

[SISTER MARGARET]: You wouldn't want them to try anything?

[JILL CHAPMAN]: No, I wouldn't want him to keep on trying if he didn't feel there was anything more he could do. I think a doctor should really be honest, which is, I know, hard for them sometimes, and say, "We've tried this and tried that--we can try this, but I don't think it will really help a lot. We can do this to keep you comfortable. You can stay at home or go to the hospital. What do you want to do?" If they gave me a little time to think, I would feel better about it.

[SISTER MARGARET]: If you thought you were dying, would you be careful who you asked?

[JILL CHAPMAN]: Well, I'd be careful with my relatives, because I wouldn't ask the relatives I'm really close to, like my aunt, my grandma, my mom, and my dad. If I was married, I guess it would depend on that relationship, too. But I hope I would be able to ask my husband. He would probably be the only relative I'd ask. I would probably ask a doctor rather than a nurse. I don't know if I'd ask someone in your position or not.

[SISTER MARGARET]: You said dying enhances your life. Does that mean that you think about it all the time? Or because you've

looked at it, it enhances your life because you know it's a reality?

[JILL CHAPMAN]: Yes, I don't have to dwell on it to realize it's there. It makes itself known. You don't necessarily have to think about it to have a reminder at times or, you know, something that just reminds you that you have dealt with it at one time. It keeps it alive.

[SISTER MARGARET]: Oh, isn't that funny--keeps it alive! As when Dr. McElfresh died, did that remind you of your own death, or did that just upset you because it was him?

[JILL CHAPMAN]: Well, it was kind of both ways--it bothered me because I felt a special affection for Dr. McElfresh, and it bothered me in another way that a man who could treat children like he had and do what he had done, and then die himself, so young. That bothered me. I felt like he had been cheated somehow, but I was still alive, and I should have croaked long before he did. I thought I'm really lucky that I haven't. Because he had no idea that something like that would ever happen to him, and I know that it could. So it reminded me of myself, but it bothered me more that he had actually died.

[SISTER MARGARET]: The reason I asked that is because a lot of people think when you have cancer, you are thinking about dying all the time--which I don't think is true. I don't think you can live that way. I don't think people live like that either.

[JILL CHAPMAN]: Yes. You can't.

[SISTER MARGARET]: And after you are diagnosed as having cancer, it has a connotation of death.

[JILL CHAPMAN]: Yes. Or sentence to die. Right you are. That would have really tested my religion if I had, and I never doubted God. I never believed that He did things like that.

[SISTER MARGARET]: Did you get a sense after a while that God really loved you? Or did you go on that basis at the beginning, or do you feel that now?

[JILL CHAPMAN]: I think I learned to appreciate that more by the fact that I was alive, later. I didn't have to live through that. It could have been worse. I could have died. I didn't, and that's pretty good. So He must have thought of me. I know He did. I never questioned that, either.

[SISTER MARGARET]: Many of the teens have had a friend die of cancer. How did it affect them?

[JILL CHAPMAN]: Well, I've known people who have had cancer and died. Their personality has influenced me a lot, and their memory has had a positive effect on me. For example, I learned to appreciate one little girl's enthusiasm for life, and how normal she was. She wasn't even normal, she was super-normal. She still continues to affect me even though she died. I have seen the situation before with the team having a friend that died. That great pain that does come, the experience of knowing that this person will die and not be with them anymore results in a greater understanding and strengthening of the person who remains. I can understand parents' hesitation in not letting their children be a part of something that everyone likes to avoid. At the same time, I feel that they are also allowing their children to experience a great loss in not letting them participate in something like that.

[SISTER MARGARET]: Would you find yourself hesitant to get involved with somebody if you thought their prognosis was poor?

[JILL CHAPMAN]: I don't think so. You can just be involved with them, or you can make it a point to be involved with the person. I don't know if I would make it a point. I'm not going to say that, but I have the desire to want to be involved with a person who I know is going to die. I knew my grandpa was going to die. That's kind of different, because he was my grandpa. We were close, but not as close as I could have been to him. I changed that when I thought he was going to die. It was Easter Sunday. We had seen him in the hospital and he was in Intensive Care. He was diabetic, but he had just had a heart attack, and the doctors didn't think he was going to live. He did, and I'm glad he did, because it made me realize, that my grandpa's going to die, and I haven't seen him in so long, and he doesn't know how I think. So I sent him a note. My dad went to the hospital every day, and every morning before school I'd write him a letter, and I'd leave it for Dad to take with him. You know, I think Grandpa wrote me back once, and it was really hard. I could hardly read what he wrote but I realized then that he really did appreciate it. And then it was about eight months, I think, before he had another heart attack and died. I did have the desire to communicate and I did follow through. I knew that I just would hate to see my grandpa die and not have him know that I really did love him. Recently I've heard of another person who's doing really badly and I haven't acted on it yet. But when I heard that, it just made me think, "I need to be there; I need to see her and to let her know that I really do care...that I am really concerned that

she is feeling that way." I haven't done anything yet, but I do feel the desire, when I know someone is in that condition, not to sit back. But these are people I've known previously, too.

[SISTER MARGARET]: Well, you could have run. Did you actively get involved with him, or were you just attuned to him?

[JILL CHAPMAN]: That was just more seeing how he was feeling about himself, because I felt like I knew some facts about his life, and I wasn't sure if he was attuned to the same thing.

[SISTER MARGARET]: I get the feeling that perhaps you have more of an understanding of what you know, like Anna here, than somebody in my position because of where you've been.

[JILL CHAPMAN]: I don't know. I wouldn't think so. I would think that you've been more places than I have.

You haven't actually gone through the treatment or anything. But maybe that should make a difference. You would feel the responsibility to get involved because you have an understanding.

Maybe I would. I might not, though. I feel a responsibility to reach out to people who are sick because I've been sick.

[SISTER MARGARET]: Do you feel the responsibility is equal to that chance of getting hurt by their dying?

[JILL CHAPMAN]: It's greater than that. It's not just the word responsibility; the desire is almost a need. I don't know what it is that changed how I felt, but I can't just sit back and say, "Well, it happened, but I haven't been sick in so long, and it's over with." And it's easy to think that, too. I have thought that now I could get out of Candlelighters. I could forget all about it. Coming back to the hospital makes me think about it, and seeing people sick makes me think about it. Oh, it would be so easy to just forget about it! I could, I'm not sick. But I can't, I don't even want to. You know, people always don't understand that. I just can't forget it. That's why I'm still down here all the time.

[SISTER MARGARET]: Many parents are afraid to let their children participate in a group because they are afraid that someone in the group will die and this will cause great pain. Have any of the teens had a cancer friend, and how did it affect them?

[NICHOLAS QUIROZ]: I never had a friend that died of cancer, so I wouldn't know how it would affect me. Well, I guess it would

affect me pretty hard, even if he died in a car accident, or if he got shot and killed. But if he could live, I would help him all I could to cope with it. Dying for me is okay because we all have to die sometime. But I'm not afraid of dying. In fact, I'm looking forward to dying because I've heard that people who died and were brought back to life by doctors said they liked it when they were dying. It was peaceful. They said they'd rather have been dead than alive.

[MALCOLM SCHORLEMER]: I think dying is all a part of God's great plan for us and I've always been prepared for death. I never had a close friend die of cancer.

[VALERIE NELCAMP]: I'm very sorry to say that I did have a friend who passed away as a result of cancer. She and I were the same age and it hurt me deeply when I was told of her death. With all my heart I had believed that both Judy and I would make it. When she died I found myself sincerely questioning for the first time my own chances, particularly of a recurrence. And if I did have a metastasis, would it quickly lead to death, as Judy's had? Many times I found myself wondering why it had been Judy and not me. Because I had identified so closely with her, the idea of death became more a reality to me personally than it had been when I first discovered I had cancer. However, I also gained a new appreciation for the life God had given me. I realized that life is something very precious--a gift to be treasured and never taken for granted. More than ever, I now want to grasp life and do the very most I can with it. I think it is because of all this that I often feel a tinge of bitterness and resentment when I see or hear of a young person purposefully doing something to destroy his health and fragile life. I can't help wondering why Judy and so many of the beautiful children at the hospital had to die when I look around at those who could care less about their lives or the evil ways in which they live them. It honestly pains my heart to see a teenager or anyone blatantly throw away the God-given health and life that Judy so desperately longed for. It all seems so grossly unfair, but we can only have faith that it's in the hands of God and that He knows best.

The Importance of Religion

[SISTER MARGARET]: Now comes the hard one: Did religion play an important role during treatment?

[JILL CHAPMAN]: That is hard to say. I was probably in the

process of reshaping my beliefs and making my religion something I could accept. The treatments were hard enough to accept without believing something that wasn't actively helping me get through my treatment. My religion at the time was more "do this" and "don't do that" than it was a real belief in God. So with my religion on the rocks, I guess it was hard for me to put a lot of faith in God to pull me through. I guess I prayed for the strength to pull myself through, and in that way my religion played an important role. Right now, dying for me is not okay, but when the time for me to die does come, my goal is acceptance. Dying isn't a reality right now, but because it is a possibility, it enhances my life.

[NICHOLAS QUIROZ]: Religion for me did play an important role because I would pray to God a lot, asking for help, that there would be no recurrences, and for help to get me through my treatments. Every time I would want to quit, it gave me courage not to quit. And so far, it's working.

[GREG WALDHOUR]: Yes, it played a very important role for me.

[MALCOLM SCHORLEMER]: I knew God would pull me through my crisis and pain.

[VALERIE NELCAMP]: Religion played an extremely important role during my treatments. I know I never could have made it through either the surgery or the chemotherapy without the comfort, courage and patience that only God can provide. I have been off treatments for 2 years, but I still look to God for the strength and perseverance I need to cope with my artificial limb and the various obstacles I must meet as a result of it. With God's help, I know I can overcome any problems the future might bring and go on to live a normal, happy, healthy, and fulfilled life.

I feel that religion is the greatest sustaining force in my life. During the time I was undergoing treatments, it strengthened me by providing faith that all I was enduring now would eventually be for some very good purpose. It has filled me with an inner peace and an ability to accept my artificial limb. I know that my problems here are only temporary and that one day they will all be forgotten. But mostly, my relationship with God has given me hope for the future--an assurance that I'll never again have to battle cancer.

I'll have to admit that, at times, I have questioned my religion as a result of my experience. One can't help wondering why God allows such things to happen. What's the point or purpose? It all seems to contradict the ways of an ultimately loving and

merciful Father. However, I try to be faithful to my belief that God has a divine plan and that one day the ever-present question, "Why?" will be answered.

[JILL CHAPMAN]: I have questioned my religion. I've worked with God, to really believe in Him, and to define Him as something I can really believe in. I always tended to question things anyway, and it never hurt me to question my religion. You have to have a religion that's workable for you, that relates to your whole person. Your religion has to satisfy all your needs, and I had needs that to me were just immense. I am a person--I can do it. So I needed my God to help me believe in myself. My religion has helped me with that.

[SISTER MARGARET]: Did you pray on it?

[JILL CHAPMAN]: Yes, and it bothered me, too, because I'd never prayed before. I just never had communicated with God on the same level as I was doing then. But I used to tell my girlfriend on the phone, "Well, this is kind of neat, because I can communicate with God and solve the world's problems at the same time." Well, all my problems, anyway, which was the world.

[SISTER MARGARET]: We talked in the first part of the discussion, about feeling guilty, that the disease was your own fault. Did you relate that to God, that you had said at one time that you wished you were sick, and that God somehow gave you the sickness? Did you see God as giving you the sickness?

[JILL CHAPMAN]: No, I didn't. I would ask Him, though, how this happened. I don't think I ever blamed Him for it. I never hated God because I've been sick, but I'm sure I questioned it. In a Sunday school class every once in a while somebody would say, "Sickness is a result of sin." I don't have a definition of sin and I never could agree with that. But I felt like all things work together into good for those who love the light. Although I didn't believe God had given cancer to me, through God I could learn from it. So I had God involved but not in the initial sickness part.

Dealing with Recurrence and Depression

[SISTER MARGARET]: Nicky? I have noted that many of the members of the panel have had recurrences. I would like to know about some of the feelings experienced during recurrence and the feelings about recurrences which may happen in the future.

[NICHOLAS QUIROZ]: The feeling during the recurrence is kind of depressing, as least for me it was, because it meant going through another operation not knowing how it was going to turn out, and starting chemotherapy over again. And it is just like when I had my recurrence, I had another month to go, before we would be finished with chemotherapy. When I found out I had another recurrence, I got really down, deep-down depressed, because without asking the doctors or anybody, I knew I would have to start chemotherapy over again. That was a real depressing time for me. The third time I was kind of depressed, but not that much, because I wasn't really into chemotherapy. But it didn't hurt that much, like it did the second time I had a recurrence. If a recurrence ever happens to me again, I feel I am ready for it, since I have had it twice before. I thought it was all gone, but apparently it wasn't.

So I am ready for the recurrence, but I don't know if I am ready for taking chemotherapy over again. I have to make a decision about that.

[SISTER MARGARET]: What helps your depression?

[JILL CHAPMAN]: A good night's sleep. Recurrences haven't made it more difficult. When I have a recurrence, I really don't dare to think about it. I only get depressed when I think that my life is going to be cut short. I get depressed at my loss in trivial ways, and in greater ways. That's the only time I get depressed, and a recurrence for me is like another time zone. It has its own circumstances; I tend to have different thought processes when I am sick.

When I really think of depression coming on is when everything's going well, and something comes along--and because of some physical loss of mine, I can't participate or someone thinks I can't participate. That's when I get depressed, and it always usually happens at night. When I wake up in the morning, I feel much better. I have a few down days. Then one night, I'll just get it all out--talk, yell at people in my head, do all kinds of stuff, and somehow resolve the problem, and I'll be fine the next day. Really the depression comes by knowing that it will take a lot to change people's minds about how I function and am normal.

[NICHOLAS QUIROZ]: I find I'm mostly depressed because I have to take treatments. Then I sit down and I think about it. And I tell myself, if I wouldn't be taking these treatments, I wouldn't be alive today. So, it's just thinking most of the time.

[SISTER MARGARET]: How have recurrences made it more difficult?

[NICHOLAS QUIROZ]: Because chemotherapy starts all over again, and it can get depressing. The first time I had cancer, I started coming in every Friday for treatments for about a year or so. That was in '74. In '75 everything was okay. In '77 I had another recurrence, but this time they played it differently--they were bringing me into the hospital for two weeks of chemotherapy, and then they were letting me out for two weeks. So far it's helped me, and it's working, and as long as it's working, everything's okay.

[JANET LANIGAN]: I don't get depressed often, but when I do, I get really low. But it is infrequent and then I come out of it and am fine for a while.

[SISTER MARGARET]: What do you do when you get depressed?

[JANET LANIGAN]: I usually have somebody lift my spirits. I talk to somebody like you.

[NICHOLAS QUIROZ]: In the hospital, I have the nurses or doctors, or the Child Activities ladies, and Sisters--people other than my family to talk to. But out of the hospital, I talk to my friends sometimes if I am depressed. If they help me, then I'm okay, but if they don't help me, I think it's a waste of time asking them. But then I just think about it myself. Most of the times it comes out positively.

[SISTER MARGARET]: What has helped your depression? How have recurrences made it more difficult?

[MALCOLM SCHORLEMER]: I would say just being alone or being with friends, has helped my depression. I don't think recurrences have anything to do with a depression. It's all a state of mind.

[VALERIE NELCAMP]: I found that the best way to overcome my occasional depression was by putting the thoughts of my disease aside and participating in life as normally as possible. I also discovered a great source of solace and tranquility in my rocking chair! When it all became too much for me to bear, I found peace in rocking and listening to music all alone. It gave me an opportunity to sort out my thoughts and put things in perspective. The second part of the question does not apply to me since I have never had a recurrence.

[SISTER MARGARET]: How do you deal with the depression in and out of the hospital? What happens? How do you come out of it?

[MALCOLM SCHORLEMER]: I've only been in the hospital 3 times

and have not had many depressions. And as soon as I am with friends, all of my troubles disappear.

[GREG WALDHOUR]: I hardly ever have any depression. I just call on God and I'm back to normal.

[VALERIE NELCAMP]: I never dealt too well with the depression in the hospital. In fact, I seemed to undergo a sort of personality change during the times I was in for treatments. I would become very quiet and withdrawn. I felt somewhat irritable and hostile towards those around me and just wanted to be left alone until my stay was over. However, out of the hospital, I was a completely different person. By immediately pushing all thoughts of the hospital aside and by simply enjoying each day, I found that I could easily overcome any feeling of depression.

[SISTER MARGARET]: When you have a recurrence, what are your feelings?

[JILL CHAPMAN]: Well, when I had my recurrences, I was a few years younger, and the people around me were as immature as myself. It was always a big deal. Somebody was in the hospital, and they kind of wanted all the gory details, but weren't really concerned about the problem itself.

Later on, when I had another reccurence, my real friends were really concerned about me. My friends knew beforehand that I was going to be hospitalized, it wasn't a surprise like it had been before. So they went to all kinds of pains to let me know how much they cared about me. Before I went into the hospital, during class the guys sang a song to me, and I got all upset because I knew they cared. My choir came and carolled at my house. That was after I was out of the hospital.

[SISTER MARGARET]: Do some of you with the most recurrences find it hard to laugh or to joke?

[ANSWER]: I haven't had a recent recurrence, but I've been with kids who have, and they often joke, and have a good time. I'm sure it helps them maintain some kind of sanity about it all. It gives them a lot of support. It helps them to get through. They're great to be around--they're the greatest bunch of people I've ever been with.

[SISTER MARGARET]: If you have a recurrence and you are hospitalized, how do your friends react to it?

[NICHOLAS QUIROZ]: The second time I had a recurrence, I had a

couple of friends who up and said they were sorry that I had another recurrence. I could have talked and talked about it to them and they would listen, but they just bore with it and hoped for the best.

[SISTER MARGARET]: Do some of you with the most recent recurrences find it hard to laugh or joke?

[NICKY QUIROZ]: My last recurrence was in '77. It's been over a year now, and it's not hard for me to joke or laugh about it. After my first operation, when they amputated the arm and shoulder, I said to myself, "I can't feel sorry for myself for the rest of my life because it's not going to get me anywhere. I've got to grow up sometime, so I might as well grow up starting now." And I laugh and joke around about having one arm, you know, one-armed bandit. My sister jokes around a lot with me. I take it, I don't mind, and when people ask my mom, my dad, my brother or sister, or anybody else besides myself what happened to my arm, it gets me mad. I'll tell them what they want to know; they should ask me. I don't mind talking about it. But I know they don't feel right asking me because I might get offended. I just want them to know that I don't mind it.

[MALCOLM SCHORLEMER]: Friends kind of draw back when they visit you in the hospital, whether you're in for tonsils or cancer.

Adolescent Cancer Groups

[SISTER MARGARET]: Do you have a local teen or adolescent cancer group with whom you can and do meet? If not, is it because you don't want one, don't need one, because parents don't encourage it, or because the staff doesn't encourage it?

[VALERIE NELCAMP]: I am not a member of a hospital youth group for teenagers, but I would very much like to be. I definitely feel that such a group would be helpful. Young cancer patients need others like themselves to whom they can relate and who can honestly say "we understand." With something so deeply personal in common, I believe that the members of a youth group could provide genuine support, encouragement, and acceptance for one another. They could also help each teenager to gain insight into his or her own emotions and problems by serving as points of comparison.

[EDDY KIMBALL]: At Kansas University, the parents' group is called PALMS (Parents Against Leukemia and Malignancies Society).

Recently we have started a youth group called YAC--Youth Against Cancer. We meet and we have had some parties and a garage sale, and they are the ones who sent me here. They paid my way. Dr. Brad started it. We elected officers. We try to meet and help each other out, and just do fun stuff. We are going to try to raise some more money eventually. There is an almost completed huge addition to the Med Center which will leave a lot of empty space. So we may get one of the larger rooms, and make it into a teen room, soundproof the walls, and put in a stereo system, TV's, and maybe a pool table, fooz ball, or something like this.

[JILL CHAPMAN]: In St. Louis, the Candlelighters' Society was started with Sister Margaret, and then Sister Margaret coerced me into starting a youth group. There were people who were interested, and we all got together and had a meeting. I had the privilege of being the first chairman. We started with 15 people and the last I heard we had a lot more than that. We do the same thing that YAC does and we establish annual events. We also have given clinic patients, especially the children, a chance to come to the hospital and have a good time. We have an annual Christmas party at the hospital, and an annual Easter egg hunt on the grounds out in the country. I think one of the major accomplishments has been to bring people together. When I was diagnosed, I didn't know anyone who had the same problem I did. Now all the kids see each other in the hospital, and siblings, friends, and relatives all have a chance to meet and interact with other people and get to know each other.

[ANSWER]: I'm not only a member of a youth group. I'm also a member of a private club of the kids from St. Louis who are here in Washington, D.C. for the Candlelighters' Conference. We had a good time. I haven't had a recent recurrence, but the other kids have. We were going sightseeing in the car, and one of the kids in the back was flipping the wig off the kid in the front. We were afraid it was going to fall out the window, and we had such a good time talking about wigs. That's one of the hardest problems kids have--losing their hair. But there they were, flipping off their wigs! So it is very helpful to talk with teenagers about the same problem you have. You don't have to come out and talk about it either--just by joking and laughing you can communicate the same feelings of understanding.

There is definitely a need for such a group.

It's hard--like I said, most of my confidants were adults. But when there's a kid you can talk to, it's like having five adults who don't understand but will listen, to have one kid who understands.

Love and Marriage

[SISTER MARGARET]: I would like to know if any of the teenagers, especially the older ones, have any thoughts on love, marriage, or the prospects of an independent relationship with another person?

[JILL CHAPMAN]: Right now, I am 19 years old, and I have 3 more years of college so marriage is a while off. I do have a relationship now with a guy.

Because I have been sick, our relationship is under a strain. He doesn't really understand, and I think he is afraid to talk to me about it. He said he talked to his dad and to his doctor. He has taken care of everything but talking to me, and I think that does make it hard on him. He said, "Well, you have had a lot longer time to accept everything." He has already half-sentenced me to death, too, and I want to get across to him that it is not like that. Just learning what I have learned helps me to know better how to love people. As far as love goes, that is hard too, but I am still working on it and this relationship we have.

If you let them go and they come back, you know that they belong to you. What I am hoping for now is that just by being the kind of person I am, we will work it out and he will talk to me. We will work out an understanding about where I stand. Or, if it doesn't work out, then I know there will be someone with whom it will work out.

[EDDY KIMBALL]: I have a little something to say on love and dating. Just this past school year, I met a girl that I really liked. At the time I was taking chemotherapy and I was out of it on Friday nights. Plus I had a lot of homework. I was taking some pretty tough classes, and just couldn't take her out during the week. But she hung by me, and now that I am not getting that chemotherapy in the summer, we talk to each other almost every night. So I just want to say that if they hang by you, they really understand. And I feel that she really understands. She talks to her parents and my parents whenever I am in the hospital, and I really think she does understand.

[VALERIE NELCAMP]: Although I really love people, I find that because of my experience with cancer, I have a little harder time initiating new friendships than I did before. For one thing, because I have had cancer, I think that a lot of people are afraid

to develop a close relationship with me. I know that a few years ago, in high school when I was really into the medicine, a lot of kids would say, "Well, you can be friends with her but don't get real close to her, because something could happen and we would end up hurt." Then I think it suddenly dawned on them that the same thing could happen to them. They were not immortal. I had another problem because of my leg. I wonder if a boy will accept me just as I am. I know that society places a great importance on physical beauty and outward appearance. Young boys especially are always making comments about how good a girl looks in a bathing suit and how she is built. I really appreciate a boy who can accept me for what I am inside. When they amputated my leg, they didn't take my heart, my soul, or my personality. I am still a person, and I think I still have a lot to give and offer. But it is still a problem because others might not be able to look beyond that physical handicap that you have.

Children Talking About Their Disease with Parents

[SISTER MARGARET]: I have a question for the parents. Do your children talk to you about their disease?

[MRS. BEALE]: My child does, and young adults I know want someone to talk to, also. Mostly, they ask simple questions that are not difficult to answer: what kind of shampoo to use when hair is coming back in? what activities are safe? what will improve their appearance?

[SISTER MARGARET]: Do any of the other parents have comments?

[MR. STURGE]: Our child was 6 years old, and unfortunately, he died 4 years ago. But I was trying to think back to the 6 months following his diagnosis, of our talks when he asked us questions, and the specific questions he asked about his disease. And our situation fits in with some of the earlier points of recognition or understanding of the child. I think my son, being at a 6-year-old level, really did not understand what was happening to him. In retrospect, we now see that he could not articulate his questions, and unfortunately, we were not trained to draw him out.

So, we tried to avoid the subject. That was a major failure of me and my wife in parenting. Now, in our parent group, one of our major objectives is to sensitize the hospital to the fact that this is one of the areas in which families need counseling, particularly when the child is young (age 1 to 6). But I guess I

came to the conclusion today that the adolescent is really at the age of greatest uncertainty, between 10 and 20 years old. They are most aware and very articulate. I wish my child had been as articulate and as intelligent as this group here today, because they really know where it is "at;" they know where they are "at;" and they demonstrated it throughout the discussion.

[Q]: After her first week in the hospital, and after completing her first series of chemotherapy, which was quite brutal to her system, my 15-year-old daughter asked me, "Why me, why did I have to come down with leukemia?" I found it quite difficult to respond to that. How would you respond to that same question, or how would you advise a parent to respond to this question?

[MR. BENDER]: It is a very difficult question. There are no real answers you can give. What I have done in my work is try to focus on it as an opportunity apart from a disease, an opportunity to do something relatively unique in our society. Especially as we get older, we become more immune to reaching out and touching other people in terms of their love, their hearts, their emotions, and I have presented it as a challenge, a challenge in intimacy and in love. There is no answer to "Why me?" Once you have cancer, I know it is difficult to accept it. So all you can do is invite the best growth and the best development.

[SISTER MARGARET]: Dr. Schwartz, did you want to respond?

[DR. SCHWARTZ]: I think you also have to say you don't know why. I think that is inherent in what Mr. Bender was saying.

[SISTER MARGARET]: Jill, do you talk to your parents about your disease or your feelings about it? Or do you feel more comfortable talking to other teens, and if so, why?

[JILL CHAPMAN]: When I was diagnosed, I was 14, and my mom went everywhere with me. She was always in the room except when they did a bone marrow or something and they wouldn't let her in the room. When I was first diagnosed, I knew she was really upset. My dad talked to me a little bit, just enough to let me know what was going on. But everything was going to be all right, so we went through the bulk of it without really talking a lot about it. Then toward the last set of treatments--we just knew what was happening, and we communicated that way. But what really struck me was that I had always been really concerned about my future: what I was going to do, what kind of career I was going to have. One day we were coming back from the hospital, and I said, "I just don't know what I want to do. I have this desire

to do something for people but I don't know what it is." And Mom said, "Have you ever considered counseling, and sharing what you feel with other people, and then if you like it just make a career out of it?" And that was the first time I really realized how much my mother really understood about what was going on. Because I just couldn't say it.

That is really what I wanted to do. And for her to know something like that about me made the communication we had, although we never talked about it, extremely close. It was different from talking to other kids. It is like apples and oranges, because they experience the same but in a separate way. Usually I feel very comfortable if the other person is comfortable talking about it and wants to know about me.

VII. Long-term Survival of Children

1. Recent Developments in the Treatment of Childhood Cancer

David G. Poplack, M.D.

Since the introduction of antineoplastic chemotherapy, approximately 30 years ago, great strides have been made in the treatment of childhood cancer. Improved chemotherapy, better surgical techniques, and more refined radiotherapeutic approaches have resulted in significant improvements in survival rates for most of the cancers of childhood. The gains made in the fight to combat pediatric cancers have not been the result of a serendipitous discovery, but rather have evolved from an often tedious and painstaking process in which insights in the research laboratory are adapted and applied for meaningful clinical use. In this presentation, drawing upon our experience on the Pediatric Oncology Branch of the National Cancer Institute, I would like to discuss some recent developments in the treatment of childhood cancer.

I will focus on three areas of investigation: childhood acute lymphoblastic leukemia; the pharmacology of antineoplastic agents; and the techniques of supportive care. I believe that each of the examples I have chosen to discuss serves as an excellent illustration of a situation in which insights and developments arrived at in the research laboratory have been, or are being, translated into clinically significant improvements in therapy.

One of the diseases in which there has been considerable therapeutic progress is acute lymphoblastic leukemia (ALL). In recent years there has been a dramatic improvement in the median survival of children with ALL. The median survival was only

3-1/2 months prior to the advent of modern day chemotherapy. However, at the present time, in most institutions, one-half of the patients are surviving 5 or more years, often in initial complete remission and free of clinically evident disease.

Two major approaches have been responsible for the improved outlook of patients with ALL: the use of effective chemotherapeutic agents in combination and the institution of prophylactic treatment of the central nervous system. A more recently utilized treatment approach has centered upon the pretreatment identification of prognostic factors. Several clinical factors are felt to be of prognostic value: the initial white blood cell count, the presence of a mediastinal mass, the age of diagnosis, and the presence of central nervous system leukemia at diagnosis. All those factors enable the physician within certain limits to gauge the severity of the disease process and to roughly estimate the child's prognosis.

A look at the results of a ALL protocol begun at NCI in mid-1971 illustrates the value of pretreatment identification of prognostic factors. Approximately 40 percent of patients are in complete initial remission 7 years following their diagnosis, 75 percent of patients who had so-called good prognostic factors (age between 2 and 10 years at diagnosis, low initial white blood cell count, absence of a mediastinal mass, and no central nervous system disease at diagnosis) are in complete remission at the present time. This, however, contrasts dramatically with the outcome of patients possessing so-called poor prognostic factors. Only 20 percent of the latter group of children are currently in their initial complete remissions.

In what ways has the identification of prognostic factors been of clinical value? First, it has enabled the physician to formulate a chemotherapy regimen appropriate for a particular prognostic factor grouping. Thus, individuals with so-called poor prognostic factors, appear to require more intensive therapy while patients with a relatively good prognosis may be spared the undue toxicity of a more aggressive treatment approach. Second, the identification of prognostic factors has provided us with a clue to what appears to be the biological heterogeneity of acute lymphoblastic leukemia.

This latter point is worth emphasizing, since considerable evidence has been accruing which suggests that there is a biological basis for what had been previously only a clinical impression; namely, that not all acute lymphoblastic leukemia cases act alike. For example, detailed immunological studies now

permit classification of acute lymphoblastic leukemia cells on the basis of their cell surface marker characteristics.

Normal lymphocytes can be divided into three immunological subclasses: T cells, which make up from 60 to 80 percent of peripheral blood lymphocytes, are characterized in the laboratory by their ability to form a rosette pattern with sheep red blood cells. They are involved in certain cellular immune reactions such as the response to skin tests and graft rejection; they also possess certain immune regulatory properties through which they either help or suppress the production of antibodies, which is the task of the other major type of normal lymphocyte, the B cell.

The distribution of the immunological subclasses among acute lymphoblastic leukemia cells differs considerably from that in the normal lymphocyte population. Approximately 20 to 25 percent of lymphoblastic leukemia patients have leukemia cells which possess T cell characteristics--so-called T cell disease. The larger group of ALL patients have null cell disease; that is, their lymphoblasts are devoid of either T or B cell markers. B cell lymphoblastic leukemia is a relatively rare phenomenon.

What is the importance of this relatively sophisticated immunological subclassification of acute lymphoblastic leukemia? First, immunological subclassification is believed to have prognostic significance, in that patients with T cell leukemia tend to have more aggressive disease. Second, classification has allowed the development of certain specific antisera developed against each of the leukemia cell types. These antisera are now being tested for their possible utility as an aid in the diagnosis of acute leukemia. Refinement of specific immunological antisera could conceivably allow more reliable diagnosis of leukemic lymphoblasts in a bone marrow sample than provided by current methods of morphological evaluation. Finally, immunological subclassification has allowed more sophisticated biological analysis of the leukemia cell.

For example, we have recently found that the T cell lymphoblasts from a young child with ALL inhibited the patient's own normal B cells from producing immunoglobulins--antibodies. This mechanism of suppression may be responsible for the low levels of immunoglobulins seen at diagnosis in some patients with acute lymphoblastic leukemia; and, conceivably, could contribute to the development of infections in such patients.

Finally, we have been examining the correlation between the immunological cell surface markers of acute lymphoblastic

leukemia cells and certain biochemical characteristics. We have found that the enzyme adenosine deaminase, which is important in the metabolism of purines, is elevated in the lymphoblasts of patients with T cell disease. This observation is exciting, not only because of the confirmation of a biochemical correlation of the immunologic differences among lymphoblasts, but because it may be of therapeutic significance. Certain specific inhibitors of the adenosine deaminase enzyme are now in the process of preclinical testing, one of which we hope to begin clinical trials with, within the year.

Thus, far from being in a static situation, relevant research in pursuit of improved therapy continues, yielding information that appears to promise significant benefits for the child with acute lymphoblastic leukemia.

Another exciting area of clinical research in which important developments are occurring is the area of the clinical pharmacology of anticancer drugs. Although a major thrust of research in this field is aimed at the development of effective new anticancer agents, we are continually learning clinically meaningful things about drugs now commonly in use.

For example, methotrexate, one of the oldest and most utilized chemotherapeutic agents, has been the subject of renewed interest, largely stimulated by the improved understanding of the pharmacology of this drug. Specifically, the development of a methotrexate assay has decreased much of the toxicity associated with the use of this drug, and has considerably improved therapy with this agent.

Methotrexate is frequently administered by lumbar puncture to treat children with central nervous system leukemia and other meningeal neoplasms. Although it is generally effective, methotrexate given by spinal tap may be associated with certain types of neurotoxicity. These toxic effects on the central nervous system range from mild to severe and in some cases may be life-threatening.

The availability of a methotrexate assay capable of measuring the levels of methotrexate in blood and other body fluids, such as cerebrospinal fluid, has permitted us to recognize that in many cases these neurotoxic reactions are the result of increased levels of methotrexate in the cerebrospinal fluid. Given this information, we began to monitor the cerebrospinal fluid methotrexate levels in all leukemia patients following their first administration of this drug by spinal tap. In these children, when necessary, we subsequently adjusted their methotrexate dose

so that the levels achieved in the cerebrospinal fluid were high enough to be therapeutic, but not excessive enough to be toxic.

The incidence of methotrexate neurotoxicity on our service between 1971 and 1972, prior to when the dose given by spinal tap was adjusted according to the cerebrospinal fluid methotrexate level, was significant. Thirty-eight percent of patients receiving intrathecal methotrexate (methotrexate administered by lumbar puncture)--in 1971 and 1972 had neurotoxicity; and in 11 percent of these cases it was severe or even life-threatening.

These figures contrast markedly with the experience in 1973 and 1974--and since, I might add--a period when methotrexate cerebrospinal fluid concentrations were monitored and adjusted as previously described. In this period only one patient manifested neurotoxicity. Once again, I think this experience is an example of a situation in which a clinical problem has been ameliorated through the acquisition of new information gained in the laboratory.

We have used our improved understanding of the pharmacology of methotrexate to develop new approaches to the treatment of central nervous system malignancy. We have developed a subhuman primate model utilizing the Rhesus monkey in which a rubberized plastic ommaya reservoir is implanted beneath the skin of the back of the animal's head.

This reservoir chamber is attached to a catheter which sits in the chamber of the fourth ventricle of the brain. The system provides for repetitive sterile sampling of cerebrospinal fluid from the monkey, and thus allows one to measure the CSF concentration of intravenously administered drugs. Using this model, we have developed an intravenous dose schedule that provides therapeutic concentrations of methotrexate in cerebrospinal fluid.

The success of this approach in the animal model has allowed us to pursue clinical studies aimed at evaluating the efficiency and efficacy of intravenously administered methotrexate in treating meningeal leukemia and brain tumors. The advantages of the intravenous route to the child, in terms of the reduction in the number of lumbar punctures, is a major factor which has stimulated the pursuit of this type of therapeutic approach.

Finally, I should like to briefly mention the advances being made in the critical area of supportive care. In recent years considerable improvements have been made in the antibiotic approach to infection, and better techniques now exist for the

transfusion of red blood cells, platelets, and white blood cells.

In addition, the role of the protected environment, specifically the laminar air flow room, in protecting the patient at high risk for infection, is being actively studied.

One of the more intriguing areas currently under investigation in our service is the use of autologous bone marrow infusions. Patients receiving very high-dose chemotherapy, which results in protracted reduction in the number of infection-fighting white blood cells, have been given autologous bone marrow infusions in order to hasten the return of the white blood cell count to normal.

Obviously, this type of approach is limited to certain well-defined situations in which high-dose chemotherapy appears to be advantageous, and in patients who have no tumor invasion of the bone marrow. Prior to the high-dose chemotherapy, bone marrow is removed under general anesthesia, and then frozen. Following administration of the high-dose chemotherapy, the patient's own frozen marrow is reinfused. This intriguing approach, made possible by recent improvements in the techniques of marrow freezing and in bone marrow culture, is now being evaluated as an adjunct to intensive, high-dose chemotherapy.

I have attempted to highlight only a few of the many promising ongoing areas of investigation that are being pursued in an effort to speed progress in the fight against childhood cancer. The improvements I have discussed represent the product of a process in which the solutions to problems faced in the clinic have resulted from insights gained in the laboratory. Clinically beneficial improvements in therapy in the future are likely to evolve through this same process.

2. Blood Needs of the Child with Cancer

Carmault B. Jackson, Jr., M.D.

I am pleased to be here and proud that you asked me to your first meeting. I have something I want very much to tell you. I bring you good news; you heard some of it from David Poplack.

Although cancer as a disease is still the most common cause of death in children ages 3 to 14, the good news is that currently, we cure--if we can say "cure" in a situation that we do not totally understand--we cure more than half of them. To do that, we have become much more aggressive with surgery, with radiotherapy, with chemotherapy and immunotherapy, and with all sorts of new techniques in our institution and in others around the United States. One of these new therapies is hemotherapy or the use of blood components. Now, although blood has more than 100 components, I would like to discuss only a few of them.

The red cells carry oxygen; the white cells fight infection--this is a simplistic view but sufficient for our purposes today. The platelets prevent hemorrhage and enhance clotting, and the plasma contains within it material that can prevent threatening hemorrhage. In blood, 52 to 58 percent of the blood is plasma. The red cell mass is 42 to 48 percent of the total volume.

The platelets and white cells make up less than 1 percent of the whole blood volume.

If one considers all hemorrhages in children with leukemia, the

routine use of platelet transfusion has reduced fatal hemorrhaging from 75 to 25 percent. The child who gets below 20,000 platelets is the one we call thrombocytopenic and is the one in danger of bleeding and also one in whom we might prophylactically like to use platelets. If we do that, we reduce this fatal hemorrhage, which is, next to infection, the most common cause of death in the leukemic patient. We reduce it to 15 percent.

Packed red cells have been available to us for some time, and are produced mainly by removing the plasma from the blood. The packed red cells still contain materials that can be sensitizing. Some of the disadvantages are that they may cause sensitization or induced allergy to platelets and white cells. We do not use these if we are going to be giving lots of blood over long periods of time. In that situation we use leukocyte poor-packed red cells. It means we have stripped away a number of the white cells and packed the red cells. Packing cells can be done by just letting them settle out and pouring off the supernatant plasma or by centrifuging. In the case of leukocyte poor-packed red cells, the yield has been improved through a device that IBM is putting on the market now. The initial research was done in our institution, so we are quite proud of our blood bank people.

The advantages of leukocyte poor-packed red blood cells are that they provide a red cell increment that contains only residual amounts of white cells and platelets, thus preventing high fevers and shaking chills. Their disadvantage is mainly that a few red cells are lost.

Frozen thawed red blood cells are next considered. These are expensive, $80 a unit in our bank, but they are very advantageous. Blood, as you know, can be kept and used with the usual preserving substances for 21 days. On the other hand, if we freeze them, we can keep them almost indefinitely. Frozen red cells are recommended for patients who require long-term platelet and white cell transfusions.

It is the extremely ill child to whom we give blood and blood substances. It is the leukemic child that you have been talking about. You undoubtedly know that 80 percent of leukemics and 60 percent of all cancer patients have anemia.

Platelets--from the French word "little plate"--when infused, prevent bleeding in patients who have a deficiency of them; a deficiency in number is what thrombocytopenia means. Excessive platelet transfusions can cause sensitization of, individual, so-called alloimmunization. Elaborate matching is required and is a bit expensive, but it is worth doing.

The white cells are primarily indicated for patients with life-threatening infection. We utilize more and more cells each year in our institution. Although white cells for transfusions are becoming available more regularly around the country, their routine use is still mainly in large centers.

Fresh frozen plasma and cryoprecipitate are used to correct clotting factor deficits.

We have in practice moved away from the use of whole blood; in fact, this past year for the first time in our history at the M. D. Anderson Clinic we did not use a single unit of whole blood.

Frozen reconstituted red cells are so clean from the multiple washings and from the freezing process that we have probably done away with the risk of hepatitis in that material. Fresh frozen plasma does carry this risk, and if it is pooled plasma, as some of the older individuals in the room remember, it is quite hazardous.

Since the 1940's we have used less and less whole blood, even in the presence of hemorrhaging where you would think of whole blood. There has been increased usage of white cells, platelets, cryoprecipitate, and fresh frozen plasma. This year we gave over 14,700 red cell infusions and more than 17,000 platelet infusions.

Occasionally there is a patient who breaks pre-existing records. We have had some patients receive over 400 units of platelets and over 140 units of red cells. These patients are now in remission. So it was worth the price.

In February of 1976, partly stimulated by Dr. R. Lee Clark, the American Cancer Society Executive Committee identified a new priority. The new priority was based on increased need for blood components as a result of more aggressive treatment--chemotherapy and radiation therapy. The committee identified an inadequate public awareness of the blood needs of the cancer patient. They identified a lack of cooperation with existing blood donor programs. I will not dwell on that; it is getting better, but it has been very difficult. They identified a lack of an ongoing blood donor program, and in September of that same year, the ACS Advisory Committee on Cancer in Children adopted a priority which then created a program called "Expediter" to coordinate a donor program.

I have one message I want to leave with you. I hope you will take this as something you want to sponsor, too. The blood needs

are great, and blood is life saving. Do you know that if everyone who is eligible in the United States donated blood once every 16 years, we would meet all our foreseeable needs? I hope you can persuade yourself and others to pay that very nominal price.

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3. Prolonged Remissions

Aaron R. Rausen, M.D.

I want to share with you what I understand you all are very, very conscious of, namely the concern about problems that may occur in children who end up as long-term remitters and, hopefully, "cures."

First I would like to mention some of my experiences as part of the Cancer and Leukemia Group B, which is one of several large cooperative groups that have undertaken chemotherapy trials supported through the largesse of the National Institutes of Health. This support has been through Federal agencies that are now having second thoughts about the type and quantity of support that has been given to these programs. As Dr. Poplack mentioned, the results that we are sharing with you have not come through intuitive leaps or magnificent genius-generated ideas, but have come about by a series of small observations being put together in a very tedious and methodical way involving much routine note taking, chart work, and other such paperwork.

Figure 1 is a chart provided by James Holland, Chairman of the Cancer and Leukemia Group B. This chart shows the progressive improvement in survival rate of children with acute lymphocytic leukemia treated in prospectively randomized chemotherapy trials beginning in 1956 (trial 01). Each more recent trial has an improved survival rate over past trials. The number adjacent to a curve indicates the trial designation. The first two digits of more recent trials are the year of onset of that trial; e.g, 6801

was begun in 1968. The number in parentheses indicates the number of children in that particular trial.

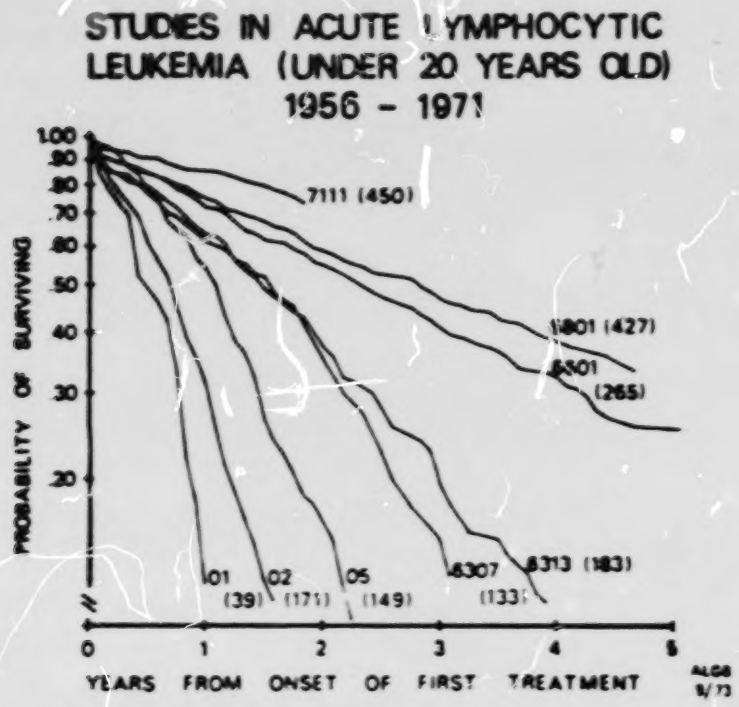

Figure 1. Survival of children with acute lymphocytic leukemia studied by Cancer and Leukemia Group B. The survival curves improve progressively with each most recent study. In the more recent studies the first two digits next to the end of the curve indicate the year of onset of the study (e.g., 6307 was started in 1963). The number in parentheses indicates the number of patients entered in the particular study.

Over the period from the 1950's until the present, the percentage of children surviving for longer periods of time has increased. In most large series of patients collected, close to 50 percent of the patients are not only surviving but are also staying in their first remission for 5 years or more.

The results graphed in Figure 1 show the abysmal results back before we knew some very simple things such as using oral methotrexate in higher doses on an intermittent basis as opposed to daily low dose.

Figure 2 is a diagrammatic representation of four possible combinations of therapy that were used in a randomized prospective manner to evaluate a variety of variables in the therapy of acute lymphocytic leukemia in childhood.

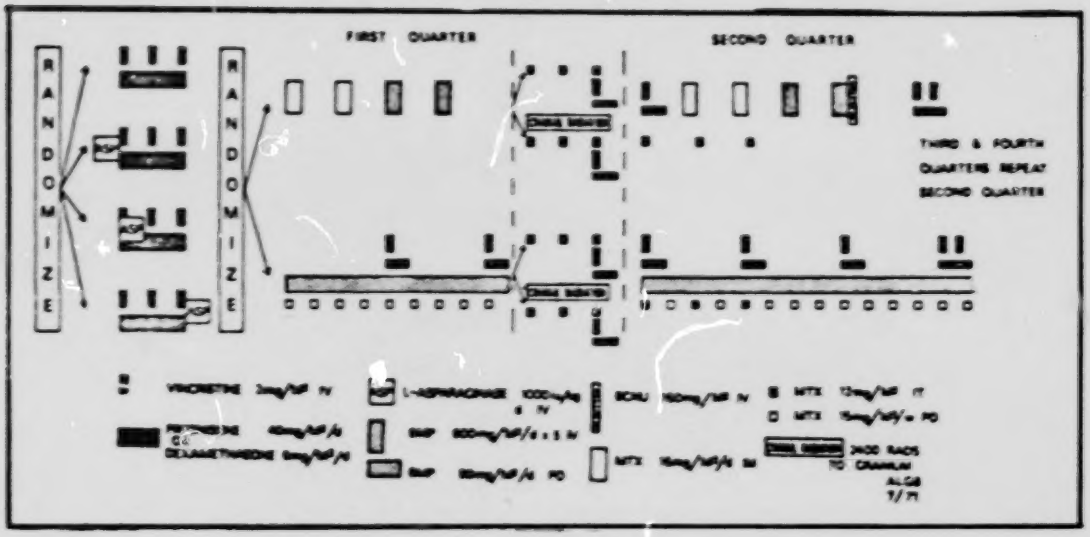

Figure 2. Diagrammatic representation of protocol 7111 for study of newly diagnosed children with acute lymphocytic leukemia. The various randomization possibilities are illustrated.

Under controlled circumstances good standard therapy was being evaluated critically against potential methods to improve results. As an example, in this study which was begun in 1971 by the Cancer and Leukemia Group B, several variables were evaluated. Was it better to use prednisone or dexamethasone as the steroid during the induction phase of treatment of acute lymphocytic leukemia to get the child into complete remission? One of the reasons for considering this possibility was experimental evidence that prednisone tended to impair neutrophil mobilization to areas of inflammation, whereas dexamethasone impaired this process less.

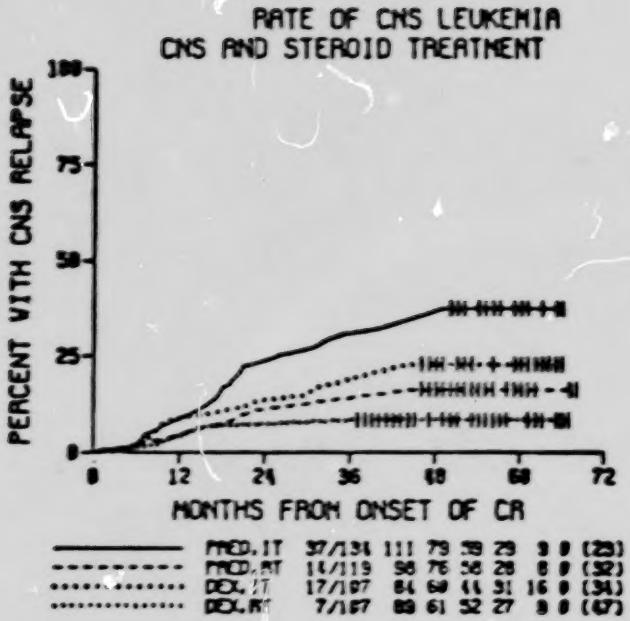

Figure 3. Emergence of central nervous system leukemia in children with acute lymphocytic leukemia treated on 1971 Cancer and Leukemia Group B protocol. Each tick mark indicates a single patient on the plateau portion of the graph. Pred = prednisone; Dex = dexamethasone; IT = intrathecal methotrexate prophylaxis; RT = cranial radiation plus intrathecal methotrexate. Ratio after each graph designation equals number of relapsed patients/total number randomized to group. Following numbers indicate number who have reached each 12-month period.

A serendipitous result found in this study is illustrated in Figure 3, namely that as far as emergence of central nervous system leukemia was concerned, it was less in those patients who received dexamethasone as opposed to prednisone.

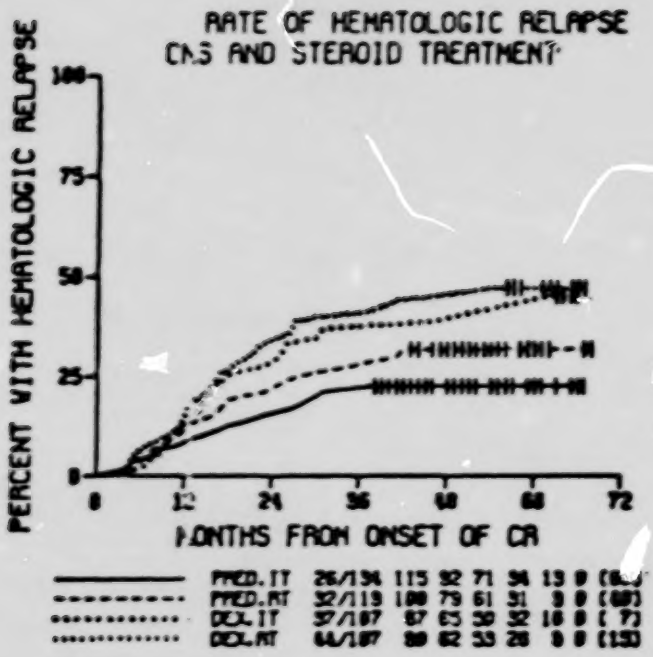

Figure 4. Emergence of hematologic relapse in children with acute lymphocytic leukemia treated on 1971 Cancer and Leukemia Group B protocol. Symbols as in Figure 3.

However, the other side of the coin is illustrated in Figure 4. As far as hematologic relapse was concerned, the patients who were receiving prednisone were at less risk of bone marrow relapse. There was no difference in the incidence of infection between those who were on prednisone as opposed to those who were on dexamethasone.

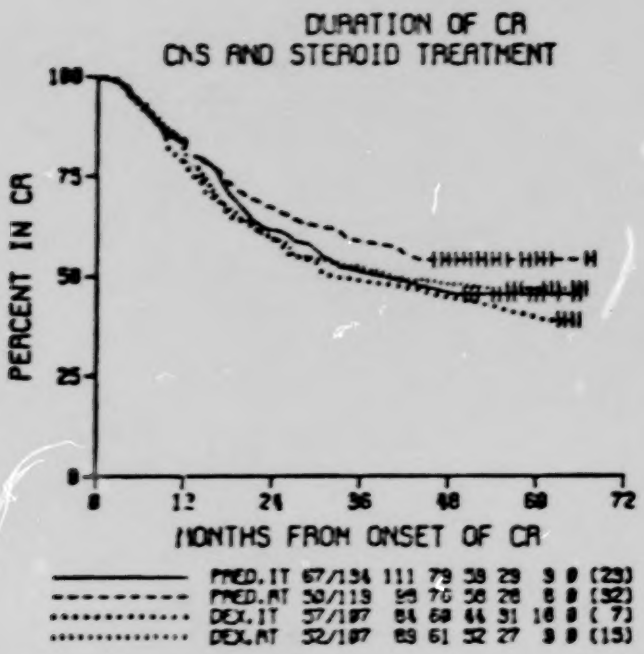

Figure 5. Percentage of children with acute lymphocytic leukemia in complete (CNS and hematologic) remission on 1971 Cancer and Leukemia Group B protocol. Symbols as in Figure 3.

The two effects cancelled themselves out, as illustrated in the close clustering of curves of maintenance of complete remission when prednisone was compared with dexamethasone (Figure 5). You will notice that all curves tend to flatten out at approximately 48 months. This trial demonstrated that there was really no difference in duration of complete remission between the two steroids but it brings up some intriguing possibilities as to the sites of action of drugs or perhaps the ability of one drug to allow other drugs to get into different sites in the individual who has leukemia.

Cancer and Leukemia Group B has been conservative regarding stopping chemotherapy. Many institutions have been treating acute lymphocytic leukemia in children for 3 years; St. Jude's Hospital is even down to 2-1/2 years of treatment. For a variety of reasons (perhaps it is good to have some variation so that there can be comparison between groups) Cancer and Leukemia Group B until recently has kept children in continuous remission on

treatment for at least 5 years. In the 1971 study no patients came off therapy until 1976. Thus, Figure 6, graphically illustrating relapse rate after cessation of therapy, is only for a one-year period.

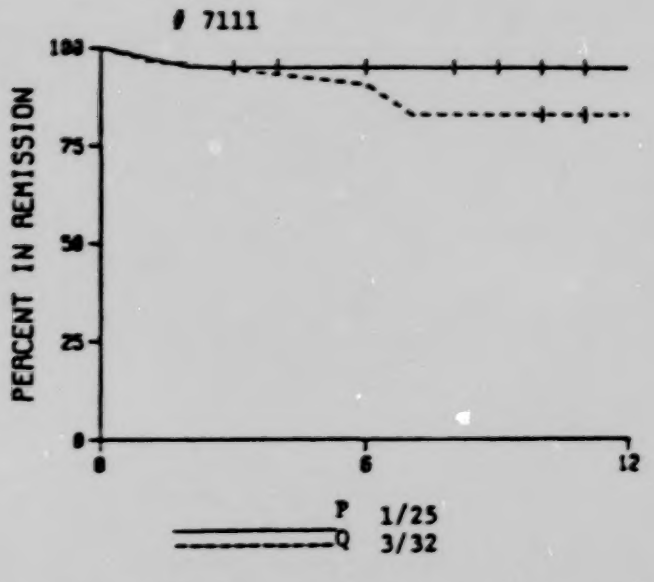

Figure 6. Percentage of children with acute lymphocytic leukemia remaining in complete remission on 1971 Cancer and Leukemia Group B protocol who were randomized after 5 years of therapy (time 0) to continue or discontinue therapy (coded randomizations P + Q). Abscissa time scale in months. Over 80 percent in each group remain in remission for the 12 months of observation to date.

These updated results show that there is no difference if you come off therapy at 5 years or if you continue on therapy after 5 years. More updated studies done on patients begun in 1974 will, in our group, try and answer the question as to whether 4 years versus 6 years of therapy will make a difference. There is very little question, however, that in the majority of patients treatment has to be given for at least 2-1/2 to 3 years under the kinds of treatment that we have currently available.

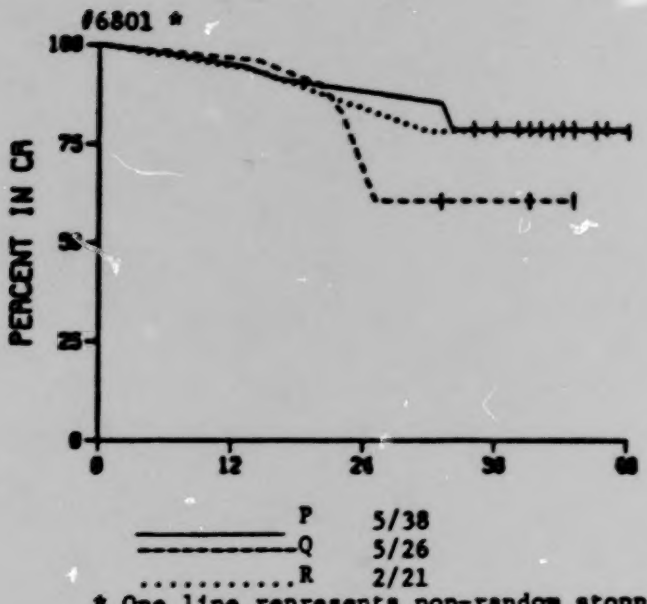

Figure 7. Percentage of children with acute lymphocytic leukemia remaining in complete remission on 1968 Cancer and Leukemia Group B protocol who were randomized after 5 years of therapy (time 0) to continue or discontinue therapy (coded randomization P, Q, R). Abscissa time scale in months.

In Cancer and Leukemia Group B, patients who were begun on treatment in a 1968 study are illustrated in Figure 7 in reference to maintenance of remission after 5 years. The curves cluster on the current update. There is a flattening out of the curves 3 years after coming off treatment at the 68 percent level. This is for complete remission. At this time, continuing therapy for 7 years appears to make no difference compared with stopping therapy at 5 years. These results are similar to those obtained in other large series that have addressed themselves to this question, even when treatment has been given for as little as 2-1/2 to 3 years. To my knowledge, there does not appear to be any advantage that has been demonstrated, as yet, for more prolonged use of chemotherapy.

Current efforts of Cancer and Leukemia Group B are addressing themselves to whether the use of moderate high-dose methotrexate

intravenously, which gives measurable levels in the spinal fluid may, hopefully in conjunction with intrathecal methotrexate, be a substitute for cranial radiation therapy in the treatment of the child with acute lymphocytic leukemia. As all of you in this audience well know, without some form of appropriate treatment to the central nervous system, 50 percent of the children who have acute lymphocytic leukemia will have a relapse in the central nervous system beginning usually after 1 to 1 1/2 years. This usually presages a relapse in the bone marrow, difficulty in reinducing remission, and, ultimately, death. With the use of a variety of forms of central nervous system "prophylactic" therapy the risk of having an emergence of central nervous system leukemia has been reduced to the 5 to 15 percent level. In my mind, the optimal form of central nervous system prophylaxis is still not defined. It would be very nice to do without ionizing radiation because of some of the problems associated with this form of therapy.

A final note will give a somber tone to my presentation. It concerns a young man, aged 20 years, who at 8 years of age had Hodgkin's disease and received radiation therapy and chemotherapy which eradicated his Hodgkin's disease. He had no treatment for 10 years. When he was 20 years of age, this past year, he developed an acute intestinal tract obstruction. The acute intestinal tract obstruction was due to a sarcoma of the small intestine which was just at the edge of his prior radiation therapy field. Second primary cancers in patients cured of their first cancer are becoming more common. Intensive investigation to see what the relationship is to the first cancer or its therapy is needed. As Dr. Clark mentioned, some individuals may have a genetic imbalance or predisposition to neoplasia when environmental stresses, such as radiation therapy, are imposed as part of appropriate treatment. Now such people are often surviving their first course of cancer and may get their next cancer which could not have occurred had they succumbed 12 years before.

CUMULATIVE PROBABILITY OF MULTIPLE PRIMARY CANCERS BY YEARLY INVERVAL AFTER THERAPY

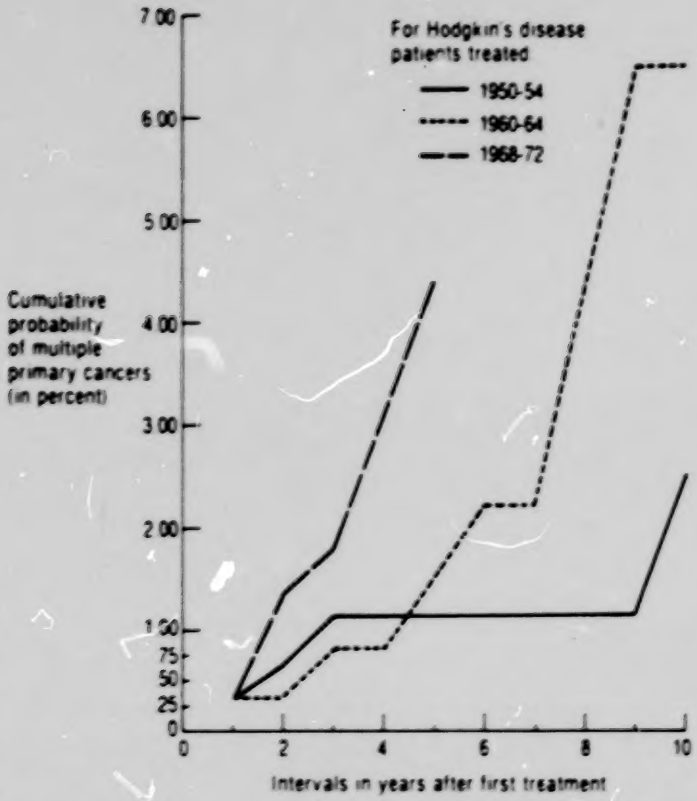

Figure 8. Risk of secondary primary neoplasms in patients with Hodgkin's disease (reproduced from: Brody, R.S., D. Schottenfeld, A. Reid. "Multiple Primary Cancer Risk after Therapy for Hodgkin's Disease." Cancer 40:1917, October 1977).

The last figure, Figure 8, is from an article in a supplement to Cancer of October 1977 that emphasized second primaries in patients with cancer. It shows, in Hodgkin's disease patients, the probability of emergence of a second primary neoplasm years after the Hodgkin's disease. The emergence of second primaries was about 2 percent 10 years after Hodgkin's disease in the 1950's. The incidence of a second primary neoplasm appears to

increase in patients with Hodgkin's disease treated successfully more recently; an incidence of second primaries in the 5+ percent range within 5 to 10 years after successful therapy for Hodgkin's disease.

The successfully treated Hodgkin's disease population is much larger today; we are retrieving many more patients who otherwise would not have survived with the less effective kinds of therapies that were used in the 1950's. Such survivors may be at greater risk because of an underlying predisposition and because of the newer kinds of therapy, or a combination of the two.

4. Education: The Issues and the Answers

June Crockett

At the University of Virginia Medical Center in Charlottesville, we use a team approach. Our goal is dealing with a living child, and the successful return of the cancer patient to his regular school in his community and back to the normalcy of his life. Just as each of us has our work or career, school is our patient's/student's career. In the past 2-1/2 years, since I have been in this newly formed position as educational consultant we have been trying to coordinate, communicate, and relate back to the home school all pertinent information from the hospital.

We have a school with teachers within the hospital, and, of course, consultants in specialty clinics who have a direct line of communication back home and in the community. Today, obstacles that prevent school attendance will be reviewed along with the concerns of teachers.

OBSTACLE #1

Sometimes parents are unable to realistically deal with the child's diagnosed treatment and prognosis. One example of this is a young 5-year-old kindergartener. His mother refused to let him attend school even though he was in remission; she slept with him in bed, and he did not participate in any of the other family activities through the summer. Her version, in spite of the support and reassurance of the hospital clinic staff was--"if we

get through these first 3 years, we are home free and he is cured." Therefore, she wanted to lock her son up in the home.

OBSTACLE #2

The patient's concern with his body image is another obstacle and factor with which we deal.

OBSTACLE #3

The school with inadequate information cannot effectively deal with the patient's special problems. What if the patient should ask the teacher a question which she does not feel prepared to answer? How do we try to eliminate that lack of information and be supportive? During the past 2 years, I have consulted with groups of teachers and with parents, either in the school, by telephone, or by letter. I have formed a mini-library of what I call "layman's language" that the patients can read. For example, when someone asks, "What is leukemia?" we can direct them to information sources such as: the Leukemia Society, NIH, or the American Cancer Society. We try to distribute this literature for the teacher, the parents, and all personnel dealing with this student. You may have already seen some of this information. We try to keep open communication between the school and the hospital, whether the patient/student is in remission and on maintenance therapy, or whether complications have arisen. The goals are that this child carry on as normally as possible and that teachers are made as aware as possible.

OBSTACLE #4

Classmates may ask the teacher questions she does not feel prepared to answer, and this is something we have to deal with.

OBSTACLE #5

Other students may ask questions of the child with cancer that may give him clues to things that his parents and doctors have not told him--whether true or untrue. An example of this was one young Hodgkin's patient in our clinic who developed school phobia for a short period of time. When she went back to school she felt there was information she had not been told. She heard from her classmates that she was going to die within 3 months. In fact, she was in remission without any prognosis of that nature.

OBSTACLE #6

The patient may become seriously ill during a class and the first aid available may be inadequate. Teachers are concerned about this and they need support to know what to do and whom to contact. The patient will be constantly catching colds from being around other children. The leukemic child is particularly susceptible to chicken pox. If that were to break out, what should we do?

OBSTACLE #7

The medical interruptions for clinic visits, the treatment complications, and contagious disease exposure all prevent school attendance.

So why are the educational needs of the child with cancer so important? Because the school performance provides the child with both objective and subjective ways to measure himself against his peers, reinforcing his confidence that he can get back to normal, or as normal as possible. Also, when the significance of remission is being discussed the medical staff treating the child with cancer should emphasize to the parents the importance of their endorsement of return to all previous activities, including school.

Successful return to regular school attendance is unlikely if the parents have an unrealistic concept of the child's prognosis, and if they are withholding disease treatment and prognosis information from the child old enough to understand. This may create an impossible situation for the patient, his classmates, and teachers. So we have tried to eliminate this difficulty by discussing each situation individually in an effort to be as "preventive" as possible.

The hospital education programs and homebound programs are good temporary measures but they should not be allowed to become substitutes for regular school attendance. This is the feeling of our "team approach." When I first came, at least 30 to 40 percent of our students were placed on homebound instruction and left there, when they could have attended their regular schools. Upon their return to regular school, they showed a great difference in mental attitude there as well as within the family.

I should point out that in Charlottesville we cover the western part of the state of Virginia, so we do serve a rural area, and a great number of our patients drive at least 120 miles one way for

clinic visits.

Other successful programs that we have initiated with our patients are: Camp Holiday Trails which is in Charlottesville. This camp is for children with a variety of health problems. Their motto is "It is ability not disability that counts." This is the first summer camp that our hematology/oncology patients are attending. Before this summer our patients attended Boy Scout camps, Girl Scout camps, etc. I had a "Back to School for the Child with Cancer" workshop which was sponsored by the American Cancer Society, 2 years ago. Some of the obstacles and concerns noted by the workshop participants were discussed here today.

I hope this will give you some idea of the obstacles to school attendance and how we try to work through these with the schools. Our lines are kept open, and we always try to deal with the "living child" in a supportive way no matter what his situation. And we do feel, as long as there is hope in the future, it makes their lives and ours worth living each and every day.

Panel Discussion

[MS. LEVY]: Our daughter was able to go to a regular camp, a normal camp, while she was still in the midst of chemotherapy. We arranged for her to go to treatment once from camp. It worked out well. So if your child is able, the more normal a situation you can place him in, the better. I do not think they should be in a handicapped program unless it is necessary.

A couple of parents have mentioned learning disabilities. I am a learning disability specialist. I have also been working in schools where I had contact with children who had cancers. And I am interested in what statistics might be available about this subject.

[MS. REAGIN]: I wanted to address the first issue that Marge Levy brought up. When I heard Ms. Crockett mention that hematology patients were allowed to go to the special camp, I felt my back go up. I don't think of my child as handicapped. He is in remission, which means he has no clinical signs of disease. I reacted rather strongly to the idea of sending him to a special camp where he might get the idea that he is handicapped. My child has a threat hanging over his head; he has a statistically very high chance of dying before his normal lifespan is out. Yet he has the full use of his limbs. And it seems to me very

important to keep him in an environment where he does not feel that he is handicapped.

[MS. CROCKETT]: That is a good point. We have enccuraged all of our patients to participate in normal activities for each Girl Scout or Boy Scout, whatever. But if you look at the brochure on the camp, it is the ability that counts, and not the disability. As Dr. Paulson, one of our diabetic doctors at the University of Virginia Hospital stated, the whole idea of the camp is not based on a handicapped child having a place to go, but rather a camp where children see that they can share an illness. They see that they are not alone, or growing up in a world with everybody else not having problems.

For example, we had a 12-year-old cystic fibrosis patient there who had never learned how to swallow his pills. And he had about 12 pills per meal to take. When he saw a hemophilic boy get his own Factor, he swallowed those pills. He said if that kid can take his, I can learn how to swallow those pills.

[MS. REAGIN]: But what I am trying to say is that I don't want leukemia to become such an important part of his life. Realistically he has to face it. He has learned that he must take his medicine, he must have treatment, and so on. But to put him in a group like that is saying to him that this is a very important part of his life. It seems to me that it needs to be no more important than is necessary.

[DR. JACKSON]: What it does say is, if you will forgive me, "You are not alone. You are not the only one singled out for this problem." A few years back I was the doctor at a camp for diabetic children just outside Philadelphia. We taught these young people to manage their problem. We talked about going back and being just like all the rest, but also that we were bringing them together to indicate that they were not alone.

At that time my oldest son was 2 years old. He came to camp with me. He was the only nondiabetic in camp aside from myself. And he would line up with all the rest of them to get his insulin, because he, all at once, was different.

[MS. PAT KAHN]: Another good thing about Camp Holiday Trails is that these kids are undergoing treatment at the time. I am talking about day-to-day chemotherapy. They come in 2 or 3 times a week. Our house officers do a rotation through Holiday Trails, just as in any clinic. And these children go to the hospital every day for treatment, and perhaps once a week for bone marrows. They are 5 minutes from the hospital. So they can

go for their treatments and then come back, and they are no different from anybody else.

[MS. REAGIN]: I know that it is emotional on my part. But it seems to me it would be different if my child were going to camp with a group of kids with his problem. However, I don't want him to think of himself as being like someone who has cystic fibrosis, or even more disabling kinds of things. I want him not to think of his potentialities as being reduced at all.

[MS. NEUMANN]: I just want to support you in your feeling. I felt somewhat similar. At the same time, David, who has gone through this whole experience and kept a very optimistic and positive attitude, said to me the other day, "Gee, Mom, I feel like a wierdo." I said, "Oh, really? Why? What is happening?" And he said, "Well, I am the only one who has to take all this medicine." I said, "Oh, well, as far as I know in your second grade class you are the only one with leukemia, but do you remember--" and then I reminded him of a little girl who had diabetes in kindergarten about whom he had immediately forgotten because that was her problem, and diabetes was not his problem. And all of a sudden his mind came around to the idea that he has his problem; someone else has a different problem. I think it is very important to verbalize these feelings. They are different; they are definitely different, but they are out there in the world living each day and doing their job of going to school. So I can see the value in your camp, especially for a child on daily trips to the hospital.

[MS. REAGIN]: Except it is not a question of being different, because my child is different in a lot of ways. As others here know, since his father is black, and we have already been through that; looking different from other people is not the issue. The issue is not being different, it is being handicapped. That is very important to us.

[MS. GLORIA WELLIVER]: I am a Connecticut mother. For the most part, we tend to think of someone as handicapped if they are crippled physically, blind, or mentally retarded. Most of us look at our children and say, "No, they're not handicapped." According to Webster's Dictionary, handicap is something that hampers a person; a hindrance; a disadvantage. Because we can't see the handicap, does it mean that it isn't there?

We don't necessarily dwell on the future of our children since we're too concerned about the present, living one day at a time. We have no guarantee that our children will survive to adulthood. Wouldn't that be considered a disadvantage? Are they not ham-

pered because of treatment, time lost from school, perhaps inability to keep up with other children physically?

I think of the time not so distant for our daughter, when she will attempt to take her place in the adult world. Is she not handicapped when she's denied medical insurance or life insurance because of her illness? What if she's not hired for a job because of her diagnosis even though she is in that state of grace called remission? Should she cover up because it's a handicap to her future?

I think of the shocked look on people's faces when they hear that our daughter has cancer. The immediate reaction is, "Oh, I'm so sorry." I want to say, "Don't be sorry, we have hope for her future." But I don't say it because not everyone understands hope. Cancer to most people is still an automatic death sentence. The physically handicapped are often able to overcome their inabilities with mechanical aids. We have no mechanical aids.

You may say, "But the handicap is only temporary while they're going through treatment." My answer is, "Is it truly temporary?" No one says, "Your child is cured." I don't argue that point because no one knows. It may be dormant for 3 years, 5 years, 7 years only to return later.

What about a psychological handicap? Knowing that you have cancer must have some bearing on your mental status. Perhaps these children don't dwell on it, but it's there. Will it at some time in their lives become an active psychosis? And isn't that a disadvantage, hindrance, and handicap?

We don't look at our child and see a handicapped person in the sense of the word that most view it. Instead, we see a loving vibrant teenager bursting to become her own person, independent of us. However, deep down I have to think that if ever she is denied a job or a goal because of her disease, then that's a handicap. Hopefully, others will see her as we do and not deny her her dreams and then I can say, "No, she's not handicapped."

5. The Child Off Treatment

Norma Wollner, M.D.

When I started preparing my talk for today, it took me about an hour and a half to answer what I thought would be 25 percent of any of the questions that you, or even I, would have. Since I have only 15 minutes, I decided that I have to limit myself to the questions that some of you have sent to me, since many are the same.

First, however, I will address Dr. Rausen's remarks regarding the treatment of acute leukemia. Some institutions continue treatment for about 5 years as opposed to other institutions that will stop at 2-1/2, 3, or 4 years. There are advantages and disadvantages to both, but I think the disadvantages of a 5-year treatment are considerable when compared with a shorter period of time. One must consider the toxicity of all the chemotherapeutic agents when given over a long period of time. The depression of the immune system is an important factor. And we also have to consider that if a patient relapses while on treatment, and there is that possibility, his chances of retrieval are much less than if he relapses off treatment. So I think there is a time in which we must all stop.

The first question asked of me is what is the chance of relapse for the various cancers and leukemia after 1, 2, 3, 5 years of cancer? Answering that would take me about half an hour. Take acute lymphoblastic leukemia. We have heard today that there are three different types of lymphoblastic leukemia: the

low-risk, the medium-risk, and the high-risk leukemia. In the low-risk leukemia, the 5-year survival rate today, with most protocols and minimal therapy, is in the range of 80 to 90 percent. For the medium-risk leukemia, it is about 50 percent. For the high-risk leukemia, it is about 25 percent at 2 years, and perhaps less in 5 years. The chances of relapse during the first year of treatment are, indeed, great--about 25 percent. The chances of relapse in the second and third years are much smaller. The chances of relapse after the fifth year are very rare. And therefore, I think that we can talk about cure, if one understands that perhaps his child will not be the one cured.

Take, for instance, very malignant solid tumors such as muscular tumors, embryonal myosarcoma, for which in the past there was only a 25 percent chance of cure and only in the very early stages. Today we know that for the early stages we have an 80 percent cure rate. And for the very advanced stages, we still have about a 45 to 50 percent cure rate.

And, in the bone tumors, for instance, a lot of progress has been made in the survival of bone tumor patients with very intensive treatment. We know that we prolong survival but we still cannot say for how long or how long it will take for the disease to return, if ever. So we don't have answers about many things.

The second question was "what are the long-term medical effects of chemotherapy and radiation?" and I think we have to consider two facts here: (1) the immediate toxicity of chemotherapy, and (2) the long-term effects of chemotherapy and also of radiation therapy. If we take the immediate toxicity of chemotherapy, we know that all the chemotherapeutic agents will kill not only the bad cells but will also damage the normal cells by causing chromosomal breaks. We know that they will also attack normal organs such as the liver and the kidneys, and therefore, we must monitor these parameters very carefully. Not all patients will be as susceptible to chemotherapy or show any toxicity. As a matter of fact, only a small percentage will.

If we take the role of surgery in producing prolonged toxicity, we know that repeated abdominal explorations or one abdominal exploration can cause multiple adhesions and repeated intestinal obstructions. We know that radiation therapy has been famous since it was the very first modality of therapy to be used. More secondary cancers have been related to radiation therapy than have been related to chemotherapy alone.

With radiation therapy, if the dosages are high, or if they are given in a short period of time, we know that the incidence of

second primary cancers is in the range of 5 to 10 percent. This percentage will probably increase as we increase the number of long-term survivors.

As for the effects of chemotherapy on the brain, with moderate doses of methotrexate I have not seen any permanent toxicity of the central nervous system. However, I have seen severe toxicity with radiation therapy as prophylaxis of the central nervous system. And I think most of the cooperative groups now are geared toward finding what is the ultimate dosage that can be given to the central nervous system to cure and to prevent CNS relapse.

So we are answering already what is known about neurological and motor coordination damage from chemotherapy and radiation therapy. Unfortunately, the truth is that radiation can induce second cancers. But I think we must remember something: before we had such intensive chemotherapy and radiation therapy, we had long-term survivors. And also in these long-term survivors we have had multiple primary cancers. We knew before. So, with the addition of chemotherapy and radiation therapy, how can we not expect this danger to be increased? Because also, we are prolonging life, and by prolonging life we are probably working with a child who has been infected with a disease, either primarily because his immune system is abnormal or because his chromosomes are abnormal or because he was born with a certain defect that will cause him to develop second cancers.

The fourth question, which is the one I have just answered, is: Can a child who is cured or is in remission for 10 years or more, be more likely to develop cancer in another site?

Five: Should a child who has cancer or leukeumia be more cautious of things like diagnostic X-rays and medications? We live in a world of medications, and I do not think anybody is going to stay away from them. X-rays are needed but I think we have to be cautious about the numbers of X-rays that are obtained. You know about the effects of radiation therapy to the head and neck area and over teeth. The dentist will only be able to provide you with information. With prophylaxis, work can be done to the mouth and to the bite through X-rays. If they have to be obtained, you have to be the judge--together with the physician--of what the limitation will be.

Six: How long should a child be followed in terms of check up? and this always brings to mind whenever my patients get very impatient and they say, "Well, how much longer do I have to come here?" I say, "Until I die." And so they look at me and they

think, "Well, that is not much longer."

A child has to be followed for the rest of his life because there is a lot of information that we must gain from those who have survived. And the information is whether they will be able to have children; how their children will turn out; what will be the incidence of cancer in their offspring; what will be the incidence of cancer or second primary tumors within the radiation therapy field or in the other areas; are there any chromosomal abnormalities that will be seen after chemotherapy and radiation therapy which will be permanent; and can this be associated, therefore, with certain types of cancer? Therefore, can we prevent this? Can we know which patients are at high risk? This will take much studying and a lot of money.

Seven: the psychological consequence. What effects have been studied or found in children whose treatment has been terminated? What should we, as parents, be doing? There were long-term survivors many years before intensive chemotherapy was used. At that time--and these were mostly children with bone tumors which were kidney tumors--and at that time the word "cancer" was a taboo. Today, we speak about cancer more freely. Even though it does hurt us to talk about it when it refers to our own children, we still communicate. Therefore, schools are more aware of cancer, other children are more aware of it, and parents will discuss it with their children and their doctors. And today we are talking about cure.

But in earlier times, nobody was even thinking about cure, and therefore, the child who had cancer was put in a special place on a pedestal and was spoiled to death. Thus, when he had to face reality and life, he was unable to do so and the results were catastrophic. Today, this is not happening, and we know that we will do much better in the future.

I have seen no long term problems in children that have come off therapy and are supposedly cured.

Another question is that some of our children are now talking of marriage. Is it medically advisable for them to marry? Can they bear children? What are the chances of these children being normal? I do recommend marriage to everybody since it is medically advisable. There will be no ill effects of chemotherapy and radiation therapy on libido and on potency, and therefore, marriage should take effect.

Can they bear children? I think this is something that we will have to see. And I remember a letter from one of my patients who

had received radiation therapy and high-dose chemotherapy written from college, "I have found a man I like and I do want children, but my question is: do you think I will be able to bear any children?" And I said to her, "I really do not have the answer. The only thing I can say to you is try and see." She did try and we saw a very beautiful baby who is normal.

I cannot answer whether the offspring will have cancer, and I do not think anybody has that information yet. There are studies being carried out with Hodgkin's disease and survivors of Wilms' tumors, but these studies include a limited number of patients and I think one must be critical of what has been said.

Last, we live in a drug culture. What is the interaction of a child experimenting with soft or hard drugs with the long-term effects of the chemotherapeutic agents? We know that penicillin and aspirin can cause chromosomal breaks. We know that some infections can cause chromosomal breaks. We also know that hard and soft drugs will cause chromosomal breaks, so I have a word of caution--if they can be at all avoided, they should be avoided. We also know that certain hard drugs, for example, angel dust, will cause permanent brain damage.

6. Questions and Answers

[Q]: A while ago, Dr. Rausen, you spoke about the evidence of second primary tumors as a result of the radiation received after the diagnosis of cancer. I was wondering if you have any research or any statistics regarding other problems as a result of radiation. Our daughter had a slipped epiphysis last year, and she had been off chemotherapy for 4-1/2 years at that time. Now she has, they say, possibly the beginning of scoliosis in her pelvis. She has a tilted pelvis, and we are going to be going through that now, this summer.

I was just wondering if there is any evidence or any statistics regarding those problems.

[DR. RAUSEN]: Well, perhaps I ought to try to clarify the comment that I made, or the perception that you have about the comment in reference to radiation therapy and the second neoplasm.

The issue is quite complex. I think everybody on the panel will agree, a prospective, close and careful, continuing evaluation of all of the patients will be necessary to answer some of these questions which are, in my own estimation, multifactorial.

Radiation therapy does have a variety of other side effects. The radiation therapists that we have been exposed to, as parents and doctors, are well aware of these side effects. They do not use

their very powerful therapeutic tool lightly. As an example, scoliosis, which may occur in a patient whose spine has been irradiated, is at least in part a function of the suppressive effects of radiation on bone growth. This is one reason why radiation therapy is used with a bit more hesitancy in a child as opposed to an adult. If there is no other suitable alternative you take this risk.

The effects depend upon dosage as well. If you use too much radiation therapy for a particular organ, you will irreversibly damage that organ. There is therefore a series of deleterious possibilities. If you look in the Physicians' Desk Reference, which I imagine most of the audience has done, every single drug that their children have had, including aspirin or Tylenol, has the potential for producing adverse reactions.

This may in part be why somebody asked me the question just today as to how do you decide who is going to be the "God" to take care of your child. Number one, when your child first became sick you did not have the time. Even physicians have difficulty in deciding who is going to be the best physician for the illness that is involved. The specialists involved in your child's care also have concern about the type and quantity of medications and radiation to use.

[Q]: Doctor, what have they learned over the years in terms of radiation? You spoke today about the advances in chemotherapy and the different results they have been getting. What have they learned, and what research has been done in the field of radiology?

Actually, more specifically, I know when our daughter was radiated, the big question was how much, and for how long, and what dose. It was never really explained to us. As time went on and we learned more about the disease and more about radiation, it was kind of scary. Now, several years later, we are coming across these problems, and we are wondering about the relationship. What I would like to know is have they made any advances in determining the appropriate amount?

[DR. WOLLNER]: Yes, I can answer that. We have, today, what we call the multidisciplinary approach to any type of cancer, and what we are doing is looking back and constantly researching what we have done. We have decreased the amount of surgery that is required. For instance, we do not do so much mutilating surgery if we can help it, because we know that chemotherapy and radiation therapy can help that. We are also decreasing the amount of chemotherapy we give. We went from one phase of giving not

much, to a phase of giving everything, and to a phase now of giving as much as is needed for the type of disease it is.

The same thing has happened to radiation therapy. The dosages were predetermined a long time ago when radiation therapy was the sole modality of treatment. Today we know that by the addition of chemotherapy you can have a superimposition of effect, and therefore a higher dose determined over a long period of time. So we are decreasing the amount of radiation therapy.

We also consider the age as far as the radiation factor is concerned, and we are increasing the interval in which the radiation therapy is given, or breaking down the periods in which the radiation therapy is given. Therefore, the total dosage is less, and the effect is the same. Yes, we are doing that, slowly, but we are doing it.

[Q]: What about secondary sex characteristics as the children grow up? I know you don't have enough long-term patients to really know a lot, but are there any statistics in that area?

[DR. POPLACK]: I think there have been a number of studies, but I don't think any single study has been adequate. This is a very difficult thing to approach, but obviously it is one of the major problems not only for the parent but the child as well. I think a lot depends upon what was the child's age when the therapy was given, and of course, what type of therapy. In terms of age, the key factor seems to be whether the child is going through puberty at the time. There is some evidence that there may be some excessive delays in the onset of puberty, for example, in children undergoing chemotherapy. However, I think the really solid data we need to evaluate the effect on endocrine functions is still lacking.

[Q]: What are the symptoms of neurotoxicity?

[DR. POPLACK]: Neurotoxicity is a very broad term, and can really be used for a number of different symptoms. Neurotoxicity with methotrexate, one of the major drugs associated with this problem, usually takes one of three forms. The first type is an acute syndrome called an arachnoiditis which occurs shortly after the child receives a lumbar puncture and the drug is introduced. The child develops headache, nausea, vomiting and may have a stiff neck; this is a transient phenomenon.

The second type is a more prolonged form of neurotoxicity. It occurs in the form of motor dysfunction. Fortunately, this occurs in a very small group of patients who receive metho-

trexate. These children can develop paraparesis and even paraplegia; not only weakness of the limbs but even paralysis. This syndrome has been linked to the presence of prolonged levels of methotrexate in the cerebrospinal fluid.

The third form of neurotoxicity, which again is fortunately rare, is methotrexate-related leukoencephalopathy. This is a process which can result in a range of symptoms including poor school performance problems, learning problems, lack of coordination, seizures, and dementia. It usually occurs in patients who have had both methotrexate and cranial radiation. Again, fortunately, it is very rare.

[Q]: I am Yvonne Soghomnian and my daughter is treated at NIH. Is there a difference if the methotrexate is given via lumbar puncture or in the reservoir, as with the neurotoxicity?

[DR. POPLACK]: There does seem to be a difference in terms of the incidence of neurotoxicity, but it is related to the dose that is given. In experiments with our monkey model, we have found that at certain levels the dose can be given at a lumbar site in the spine with no acute toxic problem. But if you give the same dose via the ventricle, via the ommaya reservoir, toxicity may occur. The problem is that the reservoir has, we feel, distinct advantages in terms of drug delivery; that is, getting the drug to the place where it is needed most. But I think enough is known now about the actual doses that can be tolerated via the reservoir so that neurotoxicity associated with the route of administration is minimal.

[DR. RAUSEN]: May I add one optimistic note? In some patients who require methotrexate, and are developing some of the signs of neurotoxicity, and, who need the therapy, there is the suggestive evidence that not all learning disabilities are permanent or irreversible. Once one comes off therapy, more improvement has on occasion occurred than can be ascribed to just the further development of the child.

[Q]: Tom Salters, Nassau County Medical Center. My son is in his seventh year of remission. At the beginning, he was given cranial radiation, 2400 rads of Cobalt 60, and also, intrathecal methotrexate. At that time, we were told that there would be a strong possibility of some side effects from the radiation. That has been almost 7 years ago. And we have been hearing a lot of talk lately about the effects of cranial radiation. This morning we saw a slide talk at NCI comparing the brain scans of a normal child and a child who had had cranial radiation. It showed in the arachnoid area that there was definite loss of brain tissue.

What kind of symptoms would you expect to see if they started to show up 5 to 10 years after radiation? Or is that too much?

[DR. POPLACK]: I was involved in a study that utilized computed tomographic brain scanning. We were interested, as is everyone else in this room today, in the long-term effects of therapy on children who undergo central nervous system prophylaxis. There have been studies which have used psychological and psychometric testing to evaluate what happens with these patients. It is important to note that it is difficult in order to ascertain whether these individuals are different from the normal population. I can give you a review of what we are trying to do, to show you some of the complexities.

First we selected patients who we knew had clinically demonstrable methotrexate leukoencephalopathy and had severe symptoms of this nervous system toxicity. We evaluated them using computed tomographic brain scanning and found they had abnormalities not seen in normal individuals or in individuals with other types of nervous system problems. We then decided to use the computed tomographic brain scanning to evaluate a large group of patients who were asymptomatic; that is, who had no clinically demonstrable effects but who had received virtually the same type of central nervous system prophylaxis.

We chose a group of children with leukemia who had all received 2400 rads of radiation. Half of them also had received intrathecal methotrexate and the other half had received intrathecal ARA-C. In late 1976 we performed computed tomographic brain scanning to see whether any exhibited the abnormalities we had seen in patients who were clinically symptomatic. And we found that roughly half of the children had some type of abnormalities; that is, they had findings on the CT scan that differed from what would ordinarily be found on the CT scan. And of course, this concerned us tremendously.

But as part of that study we also did comprehensive neurological evaluation. We found that, although there were some changes on the computed tomographic scanning, they did not correlate with those few children--and there really were very few--who showed any type of neurological abnormality. So although findings of this brain scan may be important and may signify some type of future problem, at the present time our neurological and our psychological assessments indicate no clear link with a demonstrable computed tomographic abnormality.

There are difficulties in evaluating this problem in children. For example, there is considerable disparity among people who do

psychological testing as to which tests are most appropriate. Another important concern in conducting a study is what group constitutes an appropriate control group for children with leukemia? We must remember that these are children who not only have received central nervous system prophylaxis, but they have been hospitalized for varying lengths of time. Also, they come from varied economic and social backgrounds, so the problem is complex. In a current study designed to evaluate the long-term effects on the CNS we are performing psychological tests on 3 groups of patients--patients with leukemia who have had prophylaxis (the group we are concerned about), leukemia patients who have not had prophylaxis, and nonleukemic patients who have been hospitalized who have not had chemotherapy. These latter two groups serve as control groups.

[Q]: Many of the presentations have concerned leukemia. A lot of people out there are interested in long-term survival for solid tumors such as neuroblastoma and lymphosarcoma. Can you address yourself to that?

[DR. RAUSEN]: I think there is evidence that, in the days before radiation and chemotherapy, if the tumor was removed from a neuroblastoma case at age 2, the disease was cured if there was no evidence of occurrence for 2 years and 10 lunar months (from conception to tumor removal). There was an article at that time in the Southern Medical Journal showing a 95 percent chance of no recurrence. So a child 8 or 9 months of age only needed to go for 18 months for a cure.

The problem has been compounded by the addition of radiation therapy and chemotherapy; one probably has to wait until completion of therapy and then add the number of years plus the time from gestation. Once past that point, the chances of recurrence are extremely rare if the disease has been put into complete remission for several years.

Lymphosarcoma in children is a disease in which the patient's course is rapidly downhill unless it is effectively treated. Dr. Wollner has one of the patient series indicating an even shorter period of time with no recurrence after therapy. Still, in my mind it would be best to have your child evaluated by your physician for the particular circumstances of that child in order to answer the questions of prognosis.

[Q]: We have quite a few questions on the bone marrow transplant. Is NCI working more with the autologous bone marrow than with immunotherapy?

[DR. POPLACK]: That is fairly easy to answer. We are putting a tremendous effort into the use of autologous bone marrow infusions, that is, reinfusion of a patient's own marrow when he is getting high-dose chemotherapy to shorten the period of granulocytopenia, when he is at risk to infection. We are not currently doing allogeneic bone marrow transplantation for leukemia. I think that immunotherapy is very controversial. I can only tell you that on our service, we are not doing immunotherapy because in our experience we have no evidence that it has been beneficial in acute lymphoblastic leukemia.

[DR. RAUSEN]: Perhaps there ought to be an additional comment made about the role of marrow transplantation for children with leukemia. There are biases, both for and against it, in certain selected circumstances. Still, in my mind at least, and I think in most physicians' minds, it is still an experimental technique. There are several centers that are committed to evaluating this technique. I think there are certain cases in which marrow transplantation may be an acceptable form of therapy. Appropriate candidates for consideration of marrow transplantation as a form of treatment would include children who are refractory to standard chemotherapy or, as with acute myelocytic leukemia, children in whom the chance of sustaining a remission once it is induced are slim. A suitable donor must be available. This is almost always only a brother or sister who must be tissue-typed identical (HLA + MLC compatible) to the child who has leukemia. There is a one-in-four chance that a sibling will be so compatible.

The technique of bone marrow transplant involves removing marrow from the compatible donor under general anesthesia and infusing the marrow intravenously into the recipient after the recipient has been suitably prepared. The current figures on this are low for long-term remissions, but there are individuals, both with acute myelocytic leukemia and acute lymphocytic leukemia, who are long-term survivors with no subsequent therapy. The centers doing this, such as the University of Washington in Seattle, run a success rate of somewhere in the 10 percent range for those patients who by all other criteria would have been dead without the transplant.

[Q]: My name is Neil Lasher. I am from Las Vegas, and my daughter had a bone marrow transplant at UCLA over a year ago. What do you classify long-term?

[DR. RAUSEN]: I am not directly involved with marrow transplantation. Some of my patients have undergone this procedure. As I understand it from talking with doctors such as Dr. Feig,

who was involved with your daughter, if you get past the first year, are on no therapy, haven't had graft versus host disease, you are also over the critical period as far as the likelihood of re-emergence of the leukemia. The odds are now in your child's favor.

[MR. LASHER]: We are experiencing the graft versus host problems as well as some learning disabilities associated with methotrexate and the cranial radiation. She is doing quite well emotionally, and physically she has the handicap of muscle constrictions. But otherwise physically (and mentally) she does well, except for seeing.

[DR. RAUSEN]: Here is an anecdote I heard last week when I was in Boston. There is a lady who had a marrow transplantation 4-1/2 years ago, who had almost totally debilitating chronic graft versus host disease, with the leathering of the skin and impaired joint mobility. She is now beginning to improve spontaneously. This was one of the most severe cases they ever had. I am not saying that your daughter will necessarily do well over the long-term, but there is even hope in that unusual, experimental situation.

[MR. LASHER]: She is active and swims every day in spite of her problems. But one other thing, just for other people's information, she also had chicken pox during this same time and got through that okay.

[Q]: My name is Linda Dale, from Las Vegas, also. My question is on neuroblastoma. Even though the tumor has not recurred during the last 2-1/2 years, our daughter is still on chemotherapy. What is the advantage of continuing chemotherapy for another 2 years?

[DR. RAUSEN]: It is still under investigation, and if your physicians, who are competent and capable, are evaluating things, what they are doing is probably the most appropriate method for your child. I am firmly convinced that there is a very good reason for a variety of approaches if there is no specific answer. So you are really part of the total global experiment that is going on, but with a positive end result.

[MS. DALE]: Yes, I understand that. The only thing I was questioning is that, of the other parents I have talked to, two have a daughter who has been on chemotherapy for 4 years.

[DR. POPLACK]: I agree completely with Dr. Rausen. I think that this is a situation that is being studied. But I don't think

that anybody can state that a patient with neuroblastoma should be treated for X number of years. It is unfortunate, as you well know, that there are many more questions in this field than there are answers.

[DR. JACKSON]: We have only recently learned a few magical things. For most of the afternoon we have been talking about evaluating the results of what we have done with our first long-term survivals. And it makes this a unique conference, because there weren't any long-term survivors until recently.

[DR. RAUSEN]: Yes. I recall Dr. Joseph Burchenal in 1967 reporting the total world experience of long-term survivors of leukemia as 180 to 200 individuals who had survived for more than 5 or 7 years, on or off therapy. Now that number has had a couple of zeros added on.

[Q]: My name is Lillian Johnson, from Connecticut. How well developed is the process of freezing the bone marrow? You are talking about autologous bone marrow in fusion. Would it be a benefit for children in remission to have some of their own bone marrow frozen for their future use?

[DR. POPLACK]: I think the process of freezing of marrow has been well studied. Just a few years ago, questions like: How long can you freeze marrow? Will it be viable or not? were major concerns. Now things have been fairly well standardized. There still are issues, e.g., what is the appropriate marrow dose to be given, but in fact those have been fairly well worked out via the use of animal models.

The question of taking a patient with leukemia who is in remission and then freezing the marrow is a difficult question. If you ask most pediatric oncologists, their general feeling would be that disease in some form will still be present in that marrow.

[DR. JACKSON]: We have come a long way. It is not a brand new technique; we have been concerned about it ever since Hiroshima.

[Q]: Did I understand that you've seen no evidence to date that protocols of "73" are advantageous?

[DR. RAUSEN]: No. It is still too early, with the long-term high rate of survival, to determine whether more recent protocols (1973 and later) are more or less advantageous than somewhat older ones.

[Q]: Are you saying that only 2-1/2 years on chemotherapy is still experimental--due to the fact that not enough years have passed to prove this--or has it been proven to be enough? Dr. Wollner seemed to be in favor of the 2-1/2 to 3 year treatment period.

[DR. RAUSEN]: I believe you have answered your question as I would; the duration of therapy in ALL is still experimental.

[Q]: Prophylactic radiation has shown loss of peripheral brain cell tissue. What symptoms do you expect to be showing up 5 to 10 years after radiation?

[DR. RAUSEN]: This area is currently under study by a variety of investigators.

[Q]: If a child who has ALL and is in remission experiences a relapse, 1) What are the chances of a second remission? 2) How long does such a second remission last (average)?

[DR. RAUSEN]: There is a very high chance of a second remission. Limited data suggests that up to one-third of such patients will have a prolonged, sustained remission.

[Q]: What are the "known links" between chicken pox and ALL or AML recurrence?

[DR. RAUSEN]: No link exists to my knowledge except that the practice is to temporarily stop ALL therapy on exposure to chicken pox or emergence of chicken pox, which might predispose to relapse.

[Q]: Or even of the case of a spontaneous remission of an ALL patient upon contacting chicken pox?

[DR. RAUSEN]: I am not aware of any well-documented cases of spontaneous remission of ALL or AML following varicella.

[Q]: There is a substantial difference in philosophical opinion between the various physicians. How and why does this exist? Is it a healthy situation? Are the variances based on statistical facts? How can a parent choose between M.D.'s and various opinions?

[DR. RAUSEN]: The majority of pediatric oncologists at the known centers have similar attitudes and approaches to the treatment of childhood cancer. Differences that do exist are due to unanswered questions. I believe the varied approaches to solve the

existing problems are healthy. The differences in my mind are, primarily, based not on facts but on unanswered or incompletely answered questions, and reflect the gropings of us all. The choice of various competent physicians by you as a parent should be based on your feeling secure in the patient care situation.

7. Panel Discussion: Parents' Experiences with Long-Term Remissions

[MS. NEWMAN]: The parent panelists will share some of the practical and psychological issues related to their experiences with long-term remission. The panelists, whose children range from preschool to college age, represent 22 years of experience with childhood cancer and leukemia at major and local treatment centers.

Barbara Hellenack and I did try to get a representation of the families in the metropolitan region for our panel. I must apologize for including only one man.

We are going to start by asking the panelists to introduce themselves, to tell us a little bit about their child, how long the child had been in treatment, what the initial diagnosis was, and the place of treatment. And then we will throw the panel open for discussion.

[MS. WHITFORD]: I am Sue Whitford. My daughter, Jennifer, was diagnosed just 6 years ago with ALL, and has been off medication for 3 years. She is doing fine, except for some learning disabilities, and is treated at Children's Hospital in Philadelphia.

[MS. NAEGLE]: I am Chris Naegle, and my husband is Les. And we are from Sussex, New Jersey. Our daughter, Suzanne, is 9 years old. She has had neuroblastomas, and she was diagnosed when she was 2, which is 7 years ago this August. She had surgery, radiation, and 2 years of chemotherapy. She has been off for 5 years

now. She is fine. There has been no recurrence, and the two problems were orthopedic problems in her pelvis.

[MR. NAEGLE]: I am Les Naegle, from Sussex, New Jersey. In addition to what my wife has alluded to, in almost every respect, our daughter is doing well, including school. We have had very few health problems except for the orthopedic problems, and our main concern now is what effect the radiation that she received as an infant will have on her development.

[MS. LEVY]: I am Margorie Levy, from Fairhaven, New Jersey. I have a 19 year-old daughter who was diagnosed with ALL 5 years ago. She has been off treatment for 2 years. She was treated at Memorial Sloan Kettering. She is in college; she will be a junior next year. She is leading a fairly normal life. I think there are some emotional effects, but in general I feel that she is doing everything that anybody of her age would be doing.

[MS. NEUMANN]: I am Diane Neumann. I am from New Canaan, Connecticut. I have a son who will be 8 years old next week. In November of 1974 he was diagnosed in Miami, Florida, with ALL, and was put on the Leukemia Group B protocol. He went into remission immediately, and has been in remission since then. We have moved twice, and this was one of the things that Helene asked me to mention as being perhaps a little different than most people's experience.

The first move occurred just 5 months after David went into remission. It was a company move. We would rather have stayed with our original hematologist, the doctor who had halos around his head as far as we were concerned. However, it was a very good move. His attitude was very professional, but very guarded, and not terribly optimistic. Our second doctor, at Rush Presbyterian, in Chicago, was more optimistic. Because David was in remission, he returned to preschool immediately. He entered kindergarten at a normal age. He is just completing second grade today, and is extremely, highly motivated. We attribute a lot of this to his living each day for its full value. Perhaps he would have been that kind of child anyway.

In December of 1975 we moved for a second time, and became associated with Dr. Aaron Rausen at Beth Israel Hospital in New York, because he is with the Leukemia Group B doctors.

Our experience has been one of guarded optimism. In December David will come off chemotherapy, and then we will join many of you in watching and waiting.

We have tried to maintain a sense of normalcy as much as we can. We felt proud of ourselves until about 4 weeks ago when David got chicken pox. We had full cooperation of the school nurse a year ago when the season arose in May, and he got through it with the help of six serum injections. This May again, chicken pox rose, and he assured me he never came within breathing distance of the little girl in the class who had it. Well, obviously he did, as did his teacher. When the school nurse told me that the teacher was home with chicken pox, we immediately called Dr. Rausen. We took David into the city, he had Zoster-immune globulin on Monday, and on Tuesday afternoon he came home from school with his own case of chicken pox.

It was a very guarded time for us. He came through it beautifully, is back in school, and seemingly it was uneventful. If there is one thing we have learned from this experience, it is to keep hope, and to try to live each day as normally as we can with leukemia.

[MS. REAGIN]: I am Merrianne Reagin, from Danbury, Connecticut. My son, Tony, is 6 years old. He was diagnosed in April of 1976 with acute lymphoblastic leukemia. He is now treated at the Yale New Haven Hospital. Initially, he was given a very poor prognosis, and he has now reached more that a year beyond the time that the original doctors said he would. And he doesn't have just a normal life; he has a super life. He has a great life. He enjoys every minute of it, and I don't think it is from being aware of one day at a time, because he is not really aware of the consequences of his disease. It is just that he is a super little boy.

I should also mention, I think, that I am a single parent, a situation that probably some of you share. It has its own problems in connection with taking care of a child with a serious health problem.

[MS. CURTI]: I am Sue Curti, from Norwalk, Connecticut. My daughter was diagnosed in 1976 with Wilms' tumor. She had radiation and 15 months of chemotherapy. She has been off drugs now almost a year.

Jennifer had other problems as well. She had learning disability problems before she was diagnosed. My main concern now is that the drugs and the radiation have increased her learning disabilities. For instance, at age 3, she was not speaking, and by not speaking, I mean she was not saying a word. She could not make sounds. She has been in special ed classes since she was 3 years old, and was diagnosed as retarded. Recently at Sloan

Kettering, on one of her checkups, she was seen by a psychologist who retested her and said there was no way in the world that I should have been given this diagnosis, which was a great relief to me. And he now wants to see her in a year again to retest her.

She is 6 years old now. She is still not attending "regular" schools. She goes to special ed classes for speech and physical therapy, because she is not developing from the waist up. For instance, she cannot hold a pencil very well and write like normal kids of her age. She can, however, run, climb, jump. And I am wondering what effects the drugs will have on her, as far as making her worse, or contributing to any future problems with her. I don't know if that can be answered or not.

[MS. LEVY]: I have an older child. And everybody with a child with cancer has to develop, as Dr. Wollner said, a philosophical outlook. Also, the child who becomes sick in adolescence, has to have a philosophical outlook. At the age of 16 my daughter was on the leukemia radiothon, and when they said to her, "How do you feel about your experience?" she said, "Well, I think it has been helpful. I have grown a lot. It was good."

Today, at 19, she would just as soon forget she ever had it. She had no interest in coming here. She gets upset if she has a symptom which might possibly be a relapse or might possibly be another cancer. But I am concerned with the transition of the parent of the young adult who has to take control of and deal with her own life. And particularly at an age where they may be trying to back off and deny even more, because now she is off treatment, is in college, and has a pretty normal life.

Let's say she had an eye problem, so she went to an eye doctor, and he looked at her and said, "Well, I do not see anything wrong, but I think you should go back to the hospital and have another bone marrow." Now, everybody who sees a child who they know has had leukemia is going to be very concerned. They are not going to let anything go by without wanting to look at it.

[DR. JACKSON]: This is a phenomenon that is terribly bothersome to me, and I feel it needs attention. Perhaps we could strike a nice, honest partnership here today. What you are describing is an environment in which she is expected to have a problem rather than expected not to have a problem, and maybe we ought to say, "Hooray, today is the day we are going to do it; we are going out there and we are going to prepare to live rather than prepare to die."

The eye man is obviously antsy because he knows the environment and history of his patient. So he is going to say, "Well, you had better go." It is not appropriate.

[MS. LEVY]: I think that each symptom that comes up becomes a terrible worry. For example, she had a lump in her breast, and she called the gynecologist who said he was going to suggest a breast man to go to. Well, I suggested calling the hospital first, and they saw her. Of course, each thing has to be looked into, but again, I am not sure just where this--she is taking over, you know. She is making her own calls, doing it for herself, but philosophically--and as we talked, I think Dr. Wollner did describe this.

[DR. WOLLNER]: Yes, you know, I do have a daughter with the same problem at the same age, and I think I do understand you. It is not only that. I think you go to the dentist and he will not take care of you unless he calls the physician and proves that you are in remission. But if you go look for a job you cannot find a job because you have had cancer. If you want insurance, you cannot get insurance because you have had cancer and you are a high risk. So I think we have to change the attitude of those around us.

You know, you can have so much trust in what everybody has said to you, like your mother or your physician, but when nobody else around you has the trust, you start to doubt whether this was true or not.

[DR. RAUSEN]: I think that there is a historical context that everyone here who is discussing this is reflecting: that cancer is now something that people don't have to be so terrified of. When I was growing up, if somebody had tuberculosis, they were a pariah. I think that that is all changed. And perhaps this is one positive result of everybody here being a proselytizer in this regard, and the children themselves, in various ways, having the ability to discuss this with everybody around them.

VIII. The Child with Cancer—Achieving Peace of Mind

Gerald G. Jampolsky, M.D.

I am happy to be here today to participate in this conference. I enjoyed yesterday's teenage panel, because it tended to reconfirm some of the things we are finding out in Tiburon--that age is not a factor in terms of who your teacher is; that perhaps we can learn more from creating spaces where children, too, become teachers rather than only the authorities.

I first became interested in cancer when I was an intern in Boston in 1949. We had consultants from Harvard, Tufts, and Boston University come in frequently to make a prognostication of how long a person was going to live. Two people with the same cancer would have different prognoses, and occasionally someone would die immediately and another person wouldn't die at all. To me as an intern, it became very clear what that was. It was called the will to live. I have been very interested in this will to live, because it seems to be a fact, even though we physicians or scientists are unable to measure it by putting it under a microscope. And most things are thought not to be true in the medical field unless they can be seen, touched, and measured.

There is another entity that falls in the same category as the will to live, and that is love. Love, too, you cannot put under a microscope or really measure, and yet we were hearing about it yesterday afternoon. To me, the statement, "teach only love, for that is what you are," was very well exemplified by the panel.

In 1963, because of some expertise I had in hypnosis, I had an

opportunity to meet with a 16-year-old boy who was close to being a terminal case. This boy turned out to be a beautiful candidate. He was able to detach himself from his body so that his body became only a body, and he was able to put his mind in another place in the room and really detach himself from pain.

He found this so interesting that he asked to use me as a bridge to so-called earthly reality, to communicate with what he called "people on the other side," as a way of facing death. I had never been asked that question before, but I went ahead with it. Suddenly I recognized that my own concerns about death, concerns I thought I had resolved long ago, were not resolved. He became a beautiful teacher to me, and it became clear that what some people might have called imagination was his fantasy in talking to these other people. Who was I to say that that was not real?

This experience allowed me to question what I think perhaps I mislearned about what is real and what is not real. It seems to me that we base our reality on what our past experiences have been. If we can learn to detach from some of those past experiences, we may develop a new sense of what is real.

Three things never mentioned when I was in medical school at Stanford were love, God, and spirit. It seems to me that many people now involved in holistic medicine are beginning to investigate methods by which we can combine the harmony of spirit, mind, and body. In the past, we in the medical profession have tended to fragmentize people, and have not been able to make a blending of those three entities.

It was in 1975 that I became involved in what is called "A Course in Miracles," published by the Foundation for Inner Peace in Tiburon, California. This comprises three books of metaphysical thought for those who are on a pathway of spiritual transformation. And the work with children with cancer was one of our first projects.

Now, one of the tenets of our center is that there are really only two emotions. One is love, and the other is fear. Love is our natural inheritance, but fear is something that our mind manufactures. So our main goal is to help each other let go of fear, by practicing forgiveness.

We believe that the mind can do anything without limitations, and that it is important to have a single goal--to bring about peace of mind. And our definition of healing is bringing about peace of mind. We are not so concerned about changing the bodies or cellular structure, but we are concerned about helping each other

bring about peace of mind by learning how to let go of fear. I learned that it was as important for me to learn how to let go of my fear as it was to those people I was helping. So all of a sudden, the old saying, "Physician, heal thyself," really began to make some sense.

About 3 years ago we formed a group of children, ages 6 to 18. We formed this group not so much with the idea that we thought we had something special to offer, but that we were going to ask the children for their help. We had an idea that the medical model tended not to offer opportunities for children to talk about some of the things they wanted to talk about. Often, the system and the hospital did not allow for that kind of space and time. Because the children came from so many different places, there was no kind of continuity, and we felt that if we could offer a situation, an environment where miles were not a problem, we could find a way of meeting with them.

The idea is that as you learn to help another person, you learn to become more certain about where you are. So this is what we did, and the volunteers and myself who were in this program were just as concerned about detaching ourselves from fear as the children we were dealing with. We created a horizontal model, which differs from the medical model in which a psychiatrist or counselor or doctor operates as an authority because he or she is offering some competency that a patient does not have.

In the horizontal model we are equal, and present to help--not to put any kind of authority trips on each other. We had a brief training period with volunteers. We also felt it did not make any difference as a volunteer whether you were a doctor, a Ph.D., a housewife, or anybody else. We studied words that we think interfered with fear. We found that generally our energy was focused on our worry about the past, and fear about the future, which gives us a very small aspect of the "nowness" in terms of where to operate. We had a feeling that it would be important to believe what I heard the children say yesterday: that this instant is the only time there is, that we are really not a victim of the world we live in. And our mind can change all things that hurt by learning to have inner peace which really is an internal affair, apart from anything happening elsewhere.

So, some of the words that we felt were important to detach from our vocabulary were "impossible," "can't," "try," "if only," "but," "how,"--any kind of word that would put another person in a category or that would make a judgment on another person.

We set up an environment where there was no judgment, and our job

was to see each other lovingly. In our first visit each of us talked about our various fears, and as time went on, we found that we could really help each other. For example, an 11-year-old in the group who had been through chemotherapy, was extremely helpful in sharing his experiences with a 7-year-old who had to go to school without any hair. We found that it is possible for these youngsters to go to a hospital, to go to other people's homes, to offer assistance to the children who had recently been diagnosed with cancer.

We found we could extend our group beyond cancer and involve other children who have catastrophic illness. And the children decided they would like to write a book for children. You have seen it on the table upstairs as a rough draft, There Is a Rainbow Behind Every Dark Cloud. It includes the pictures they have drawn about their experiences, but it also gives advice about what to do, how to deal with death, how to deal with lonely times in the hospital. About a year and a half ago, we made a presentation to the Candlelighters in San Rafael, and they became very interested in our project and asked us if we would expand it to include siblings. So we did this. The group took off like gangbusters. Brothers and sisters got together and talked about their own problems of coping with family stress.

Later we were asked by the Muscular Dystrophy Society to form a group for them. Muscular dystrophy is a disease children get usually when they are about 4, and they usually die when they are around 16 or 18, and we have been using the same principles as with cancer patients.

The same principles seem to be involved, regardless of the form of the illness, namely, that the mind has no limitation. For example, a 17-year-old boy was in a coma for 81 days following an accident where a truck hit him when he was on a bicycle. The physicians and the medical staff felt that this boy was going to be a vegetable. He came to us with a moderate degree of spastic paralysis, where the conventional physical therapy and occupational therapy seemed to have reached its maximum. We do a lot of things called imagery, and active imagination similar to what you have heard about hypnosis.

This boy began to develop an imagery picture at night--seeing himself walk, seeing himself playing basketball, seeing himself cross-country skiing--and we found that much of the spastic paralysis began to dissolve. And indeed this boy went cross-country skiing last winter.

A 7-year-old boy came to us because he was upset with his

physician and with his mother. The physician did what most people are doing these days, being very direct with their patients. When the patient asked, "Am I going to die from this disease?", the doctor wasn't able to guarantee him his survival, although he felt things were going okay. And his mother didn't guarantee him. Then he came to our group and talked about some of his thoughts. The other people in the group, who ranged from age 6 to 18, were extremely helpful in sharing the kinds of anger and frustration that they had experienced. They found they could be more helpful working with each other than with the psychologist, the psychiatrist, and the pediatrician.

At times we meditate. At times we pray. If someone is not with us, we send love to that person. We attempt to quiet our minds, and to create pictures similar to those of the Simonton method in which patients create pictures of white cells swallowing cancer cells.

We talk about death. As you know, children tend to communicate through nonverbal means. Certainly drawings are one means. One of our children drew himself diving off a diving board and disappearing, and then he said, "No, I can think of a better way of explaining death, and that is--." He turned the page over and said, "It is the infinity of whiteness."

Some drawings are of people on the gallows being hung. Again, it doesn't make too much difference what the content is. We give the children permission to talk about whatever they want and not feel guilty about it. Our job is to help each other get rid of fear and guilt.

Some drawings are of heaven and the cemetery. So often the medical model only offers one option in terms of looking at death, and that is its finiteness. That is the end of the road. We do not feel that we know the best way to look at life and death, but we do feel it is important to create options so people have choices.

One child drew a picture of an angel going up to heaven, and there is a little cemetery with a devil down at the bottom saying, "We lost another one." This is what death means to children; the infinity of light and love.

We work with dreams, too. Greg came in with a constant nightmare he had had for 1 week, and I asked him to draw the nightmare. He drew a picture of himself climbing a ladder going to nowhere, and a space machine with gremlins on it throwing rocks at him, trying to knock him down.

At this time the medical staff was considering whether they should offer another drug, or whether they were at the end of their armamentarium. The parents hadn't quite let go, and it seemed rather clear that this boy was ready to let go. I suggested to him that it is possible to have a dream end in a very pleasant way. When you make a dream, you have the power to make it end any way you want, and I suggested he could draw a picture about how he would like that dream to end. As you might suspect, he did draw a picture of himself climbing a ladder going to heaven. So there was a connection.

As you know, all of these children, as far as I am concerned, suffer from separation. They need a sense of being connected, so he drew a picture of himself going to heaven, and he was very clever. He put himself inside the space machine and made it go around very fast, so all the gremlins had to fall down, but he was a very gentle child, so he put the gremlins in parachutes so they wouldn't get hurt.

A professional cartoonist visited us a couple of times. He got some information from the children and drew some cartoons that helped exemplify their feelings of what it is like coming to a hospital.

Even in children's facilities, where much is happening at night, and there is good communication, many of the children feel a sense of loneliness at night. Many of the children feel that night time is when they would like to talk about their feelings, and frequently they find that our medical system does not seem to allow this to happen.

The children have taught me that it is possible to create a sense of timelessness, where this instant is the only instant there is. That means there is no past and no future. We find that many of the children have been extremely helpful to their parents, by helping their parents get rid of past fears and future worries, by helping them detach from the past and future and living each moment as it is--a premium moment. The children have also been helpful, because they recognize perhaps better than we do, that our minds are filled with hundreds and hundreds of tapes of various motion pictures. What they are learning to do is to erase all the tapes, and instead put on what they really want to experience. You can put in your mind what you really want to experience. If you really want to experience peace of mind, what you become interested in doing is putting all of your energy into giving.

A fascinating thing happens when you are in the process of

putting all of your energy in giving, namely, you do not perceive yourself as ill, and you experience peace of mind. But as soon as you become concerned about what you are going to get, or what is happening to you, and why you are not getting something, you are suddenly in conflict and in pain. Again, a statement about pain. It is my strong conviction that pain is a learned phenomenon. Suppose we are on our way to the airport and we see a terrible accident, someone wanders out of a car kind of dazed, and we stop our car and want to help. We see them bleeding profusely from an artery that is torn, and we point and say, "Hey, mister, you are bleeding from there," all of a sudden that man will look down to his arm and will start screaming with pain.

Now, he is screaming with pain because his mind looked down there and said, "Anything that bleeds like that causes pain." However, just the second before, he was not in pain because he was not perceiving pain. And it is possible, using imagery techniques, to help children detach from some of the previous kinds of experiences they have had, in terms of painful shots, vomiting, things of this sort, by just changing our belief structure; detaching from our past feeling.

We find that most of our children choose not to wear caps. They seem very comfortable without them. A girl aged 11, was referred to us because she was playing volleyball in school, and her wig was knocked off, and no one in school knew that she had cancer and was under treatment. She was completely devastated, ran into the classroom, and hid under the desk, and then ran home and refused to go to school for 2 weeks.

At the time we saw her, she still was not in school. So at her first visit to our meeting, I asked those among the group, who had lost their hair to raise their hands. Of course everyone raised their hand, and a great big smile spread across her face. She knew then that she was not alone.

Another thing that is important in terms of getting rid of these past experiences, is making use of the imagination, and I would like to suggest you do this for a moment. Just close your eyes for a second, and imagine there is a great big container in front of you, and in that container I would like you to experience putting everything that you can possibly think of that you are guilty about, every experience you have had that is painful, and every fear that you have.

Then, go outside, and allow a large balloon to be filled with helium, to be attached to that container, and let it disappear into the sky. That is a very quick, simplistic method of

detaching ourselves from the fears we have. We know we are supposed to urinate every day. We know we are supposed to have a bowel movement every day, but none of us really pays very much attention to clearing out the toxins we put in our mind with regard to fear, anxiety, pain, and guilt.

Joe is a 13-year-old boy whom I saw a few months ago up in northern California, in the town of Hoopa. He had been run over by a tractor. He was blind. He was unable to talk. He could not sit up and down or crossways. He had a spastic paralysis in the right side, and could barely move the left hand. He was to be transferred the next day to a Los Omedas Hospital in Los Angeles, that specializes in neurological problems. I shared with him two things that our group had been doing, namely, that we thought the mind could do anything, and we are not really confined to our body. We are a spirit, not really confined to our body, and that minds can communicate with each other.

I taught him how to do telepathy. I could send him colors like blue and red, and teach him how to do this with 80 percent accuracy. So, he began to learn that minds can communicate with each other. I also told him two other things. I suggested to him, as some of the other children had been doing, that he could develop imagery at night, seeing himself walk and talk. He might find that if he used his imagination, and could find an opportunity of helping another person, he might feel differently about his illness.

Well, I visited him 2 weeks later, and I took one of our children with us who had been through this kind of coma, thinking it would be a motivating factor. But the mother told me that she had had this experience with Joe: one day there was a 2-1/2-year-old black boy, Larry, who was crying incessantly from brain damage. Drugs did not seem to stop him from crying, and holding didn't seem to stop him. She remembered what I had said about using the imagination. So she picked Larry up and brought him over, and just plopped him on Joe's lap. Joe didn't know what was happening, and not knowing what to do, he took his one good hand, his left hand, and began to gently soothe Larry.

Within 1 minute, Larry stopped crying. The nurses and everyone came over to see what was going on, and the mother described the scene that you see here. It seems that both boys put their bodies in check, and went to a higher plane, where they were just concerned with loving each other. It seems to me when you are loving another person, you perceive yourself quite differently.

In summary, it is possible to create an atmosphere, both inside

and out, of a hospital environment, where we are concerned with healing, defined as letting go of fear. We are doing this by helping each other. We are also working with the parents in the same way.

The Center for Attitudinal Healing is now involved as the hub of a national telephone and pen-pal network for children who have catastrophic illness and where children around the country are helping each other through the phone.

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QUESTIONS AND ANSWERS

[Q]: I am Judy Sturm, from St. Louis. I was interested in Dr. Jampolsky's remark about teaching the patient how to get relief from pain by transferring his thoughts to things outside of his body. Can parents do this? Can parents be trained to carry this on with their children?

If so, what type of image would you use? How would you go about this? Can you give a 2-minute course in that?

[DR. JAMPLOSKY]: If we accept the premise that minds can connect, then I would suggest that parents use the same imagery technique as a child. In that way they see their child not having pain, and not vomiting. To do that, again, one has to get rid of past experiences. Many of the children mentioned yesterday that they begin developing certain symptoms just at the very thought. It was like the Pavlovian reflex of a dog salivating when the bell rings.

So, what we parents, doctors, and health personnel can do is develop the same type of picture as the Pavlovian dog; namely, develop a picture where you see the children not having any problems. It takes a tremendous faith in knowing that it will be helpful. It takes that kind of positive approach, where you are saying: "There are no doubts. I am going to develop a positive picture of seeing my child get well. I am going to see him going through this drug with minimal reactions." We suggest 5 minutes before bedtime for the parents and child to communicate with each other silently, just maintaining this kind of mental picture.

[Q]: My name is Dick Chasse. I am with the Medical College of Virginia, with the program in cancer rehabilitation, and I also work with the parents of ASK.

I am not so convinced that the pain children experience is totally one of mind over matter. I have seen too many children come in before diagnosis and point exactly to where the tumor is, due to the pain being caused.

I don't think we can teach them the mind over matter response. I do believe that we can, as the doctor proposes, teach children to respond in a more positive manner and thus lower the anxiety that goes with the pain. Perhaps we can talk with physicians and encourage them to use proper pain management in the treatment.

[DR. JAMPOLSKY]: I was impressed after World War II and the Korean War that those prisoners of war who tended to die were those who were reality oriented. To them, the pain, the beatings, the lack of food were all very real.

The people who tended to make it were those who made use of their active imagination. They detached themselves from where they were, and began to picture themselves on fishing trips in Virginia or elsewhere. Those were the people who made use of their fantasy life and seemed to survive by detaching from reality.

[Q]: If a patient is told that he can do anything with his mind and yet, using the technique, he cannot reduce pain, how do you handle this without producing guilt?

[DR. JAMPOLSKY]: The way one produces guilt is by trying to change another person or by inferring that what the other person is doing is wrong. Our job of helping people is not to change people but to extend love and acceptance to them without making judgments. So if a person is still having pain, our job is not to say that he is doing something wrong, but rather it is to help him accept the pain, to help him recognize that we accept him and

that what he is doing is all right. Whenever there is guilt there has to be someone who is innocent and someone who is guilty, and frequently in the doctor/patient relationship it is the doctor who is innocent and the patient is made to feel guilty. I feel it important and essential that the patient not be made to feel guilty. This is done by totally accepting him, not making a judgment on him, and recognizing that he has not done anything wrong.

[Q]: Dr. Jampolsky, suppose a patient undergoes your technique and is told that he can control pain, then using your technique he is unable to control it. How do you handle that particular situation without producing guilt in the child or older patient?

[DR. JAMPOLSKY]: Most of the time we talk only about our successes. We tend to see everything, including pain, as a possible learning experience rather than a problem. So it may be that we are choosing to hang onto that pain, not because we are doing something wrong, but because it is our lesson at that point.

So, we offer many other ways of dealing with the problem. One important way is to work with oncologists. Many of the children are on pain medication. Often, however, the pain medication is not working as well as we would like it to work on an outpatient basis. And it is advantageous if you can get the child to participate at any time. But our whole concept is to see everything that is happening to us as a learning experience from which something could be learned about oneself.

[Q]: Would you use heroin for pain control if it were available?

[DR. SCHWARTZ]: I would give it a try.

[Q]: Don't you think it should be legalized for cancer pain control?

[DR. SCHWARTZ]: I think it should probably be made available for some experience besides the English experience. I have heard a lot of good things about using heroin. However, I personally would like to gain some experience on my own rather than just making a blanket statement like, "Yes, if it is needed."

I personally also find that for pain control the use of intravenous infusions, analgesics like morphine, biothorazine, allow the patient to be alert and communicative and comfortable. So I have not had a great urgency in my own clinical care to look to other agents. That doesn't mean I wouldn't like to give it a try, because I feel we ought to try these things.

IX. The Parents and Treatment

1. The Parent as Part of the Treatment Process

Jordan R. Wilbur, M.D.

Over the last 10 years, we have been involved in having families together on an oncology unit to help care for their own children.

The concepts and ideas presented today are an amalgam of what we have learned from patients, their families and staff members, especially our nursing staff, over the last 10 years.

A family-oriented unit for the care of children and young adults with cancer requires a special group of physicians and nurses to be successful. Nurses who devote their full time to the care of children with cancer, and their families, are the vital core of such a unit.

As a beginning we must define our goals when we work with a family who has a member with cancer. On our unit, we think in terms of three primary goals. First of all, we see whether we can eradicate the disease with minimal residual toxicity. Second, we want to help maintain as normal a lifestyle as possible, not only for the patient but for the family as well. In order to accomplish this, our third goal is for the patient and the family to be as informed and knowledgeable as possible about the disease, so that they can be active participants in both the care and decision-making.

The guiding philosophy of such a unit includes the concept of the primary care team, a commonly-used phrase these days. A primary

care team in our view is the patient, the family, the doctors, and the nurses, even though a lot of other people are involved as well. They are all there with a common goal--to help the patient get well.

Since we are all working towards a common goal, each one of us should contribute whatever we can to achieve it. Each patient is to be treated with the expectation that we are going to be successful in eradicating the disease, but with the realization that it is not always possible. Most importantly, the second philosophic point is that members of the family should continue to maintain their responsibility to their child, whether in or outside the hospital, so that at the hospital the child is not turned over to the staff for total care.

Each family on our unit shares the responsibility of care with the staff in the hospital. I think this is a concept which is not prevalent in many hospitals. I would like to describe examples of the contributions people can make that are part of the routine care of children and families, but that can be done in the hospital.

The concept I want to emphasize is that families do have the opportunity, if they wish, to have family members present at all times in the hospital. They can remain involved in the care of their child, just as they would be at home. Parents can continue with the usual routines of parenting: feeding, bathing, entertaining, and disciplining their children. All of these activities can go on in the hospital just as they are usually done at home. However, the responsibilities are shared with the hospital staff, so that parents do not feel that they have to be there to do these things at all times, but simply have the opportunity to do so whenever they wish.

Now when I talk about the family, I don't necessarily mean just the parents. The family may mean a father and mother, certainly, but it may be a brother or a sister, a grandparent, an aunt, an uncle, or a neighbor who is very much involved. They may help with simple activities such as feeding or bathing a child.

A slippery baby is often a challenge to bathe, especially when an IV is in the foot and you have to keep the foot out of the water. But parents who learn how to do these things in the hospital can take the same child home with an IV still in place, and having learned how to give IV medications while in the hospital, can do so at home. They thereby can avoid hospitalization time and keep the family together at home.

The children can play with other children in the hospital. Sometimes they have to be directed or disciplined, as they would be if they were on the playground or elsewhere at home. Fathers or mothers may be present to help with that. Children at our center are encouraged to be up and about in their regular clothes.

School goes on in the hospital even though many of the children do not like to go to school. It is the parents' responsibility, if they are present, to see that their children attend school. It is not the nurse's responsibility or the doctor's responsibility, because they're not usually responsible for sending a child to school. It is normally the parents' task to make sure the children do their homework in the hospital.

Parents can help in special situations and there is a need for administrative flexibility. For example, one child had leukemia and chicken pox at the same time, and was in isolation. One of the parents' roles in this situation was to help the child escape out the window to play outside, since the child could not go through the unit and expose the other children to chicken pox. There was access out the window to the outdoors, and there was no reason the child couldn't go out with assistance and play outdoors, even though she had chicken pox. Obviously parents as well as brothers and sisters serve all sorts of useful roles in helping to care for the patient.

On the other hand, if a patient is a young adult with a small child, it may be of value to the patient or simply necessary for the child to stay in the hospital with the patient. For example, a woman originally diagnosed in 1969 with inoperable rhabdomyosarcoma of the nasopharynx was successfully treated. She went on to have a child. At one point there was recurrence, and she had to come back for hospitalization, surgery, and subsequently chemotherapy. She was then a single parent, so the simplest solution for her was to bring her child with her to be cared for by herself and others in the hospital.

Parents learn to do simple things like giving oral medications. In the hospital, by giving the child's medication, the parent has an opportunity to find out what problems will arise when he or she gets home and tries to give medication. Parents can also learn to prepare and give certain intravenous medications through a needle left in place. Many of the patients can now receive their chemotherapy on an outpatient basis, whereas in the past this treatment required hospitalization.

Part of the care given by the staff is to teach families about

medications, the diseases, and in general, how to care for the patient. On the other hand, it is part of the family's responsibility to teach the staff about the particular way they would like their child treated. In addition, children can learn to take their own medications, and some prefer to do so, particularly when the process hurts. The staff can teach them the right way to do this.

If necessary, parents can learn to manage nasogastric feeding tubes, and the automatic pumps that control the amount of intravenous fluids. We can teach parents and patients to fill and run these pumps, so that patients receiving hyperalimentation or some other constant infusion can leave the hospital and go home or out to the store while hooked up to the pumps.

Sometimes the situation is more complex, such as the case of a boy who had an infected sternal splitting incision which was going to require several weeks of hospitalization once he had completed the initial intravenous medication. His mother learned how to irrigate his wounds and manage the care of the wound, allowing the child to return home to complete the healing process. However, both the parents who are involved in caring for their children and the patients themselves should feel confident that the care can be managed by the family before they are sent home from the hospital. When care can be provided at home, it reduces both the stress and costs of hospital care.

Children can also learn about their diseases. They like to see what their tumor cells look like under the microscope, what their blood cells look like, or what is being done in the laboratory. If children know why and how things are being done, that makes it more tolerable for them to undergo all of the necessary tests.

One of the traditional bothers in hospital care has been reverse isolation for patients who have low white cell counts. They may well be an unneccessary exercise in frustration. For the last 10 years, we have had many patients with absolutely no granulocytes in their blood counts. We have allowed them to be in an open ward, at home, and at school. We have not found an increase in infection rates, because the risk of infection is primarily from their own bacteria in their own intestinal tract. However, we still advise families to watch out for exposure of the patient to chicken pox or measles, if they are susceptible.

Family members, including siblings, are encouraged to stay in the hospital, which means that we provide sleeping accommodations for them. We normally provide a cot for a parent. However, sometimes the parent and child end up sleeping together. If that is

a normal pattern for them at home, why not in the hospital? Sometimes the child ends up on the cot and the parent ends up on the bed. We also sometimes have three children in a bed, and the parent in the cot, or vice versa, depending upon how many siblings happen to be there at the moment.

The food on the unit is served family style. It comes up on hot and cold carts that stay in the unit for 2 hours for each meal. The staff or parents can provide and serve individual portions for the children from the carts. Those children who are able can serve themselves. If they do not feel like eating at the time, but think they might later, the food is put aside. The families have their own refrigerator, stove, and microwave oven, so they can keep and prepare food at any time, 24 hours a day.

Another policy, which has proven to be valuable for both patients and family members, is that all tests and procedures are done in a setting in which parents are welcome, but not required to be present. The treatment room is always open to the parents. In fact, there is no place, except general surgery, in which patients and parents cannot be together if they so wish.

Patients can participate in a surprising number of tasks. Our chemotherapy nurse, during the usual search for the vein, may encourage patients to help select the vein and start the IV. They can also become involved by helping to draw their own blood, or they may ask to push in their chemotherapy dose at a rate that is acceptable to them, but under supervision. It really makes a difference to the patient to have a little control over how this is being done. During a bone marrow procedure or spinal tap, sometimes parents are present and can be very helpful. At other times, they may not wish to be present. Some parents wish to be present but not to watch. The choice is available for each family to follow the method that seems best to them. Sometimes the child wants the parents there; however, some people have a low tolerance, so you have to work out the best arrangement for everyone concerned. At times, the father is in the middle of everything and the mother is not. We have had more fathers faint in the treatment room than mothers.

Even when a child is critically sick, at no time do we say, "Oh, please, step outside, your child is sick," or "Please step outside, we are going to do this or that." We tell the family what we are going to do, and they are welcome to step outside or not, as they wish.

Daily staff rounds are conducted at the bedside. During the rounds there are discussions involving patients and family mem-

bers who are present, as well as physicians and nurses. So we all have an input into what is going on and what is planned for this period of time. The medical record is open to everybody in the family: parents, patient, physicians, and nurses have equal access to the medical records, and can look and ask questions about test results and staff notes. We work to maintain good communications between the staff members and the families about all aspects of care to avoid the problem of having families learn information by first reading it in the medical record.

Everyone is a teacher: parents teach us about their children; children teach us their needs; staff members teach families and patients about their diseases and the treatments. So everybody continues to work together for a common goal. The benefits of this approach are numerous. The family is often able to provide some care outside the hospital that usually would require hospitalization. For example, there are ways to cope even if there are many medications that can be given through a heparin-lock needle. One of the mothers who was giving intravenous fluid to her child at home, said she would hang the IV bottle on the curtain rod, and the boy could play or sit on the couch and watch TV, while she did her housework. Essentially, the mother was able to carry out regular activities at home while her child was receiving a long course of antibiotic therapy.

Enough can't be said about the importance of our oncology nurses, because there could be no such unit and no such family-centered philosophy without their active involvement. On our unit, we give rainbow-heart pins to those nurses who survive a year in the program. They are very proud of those hearts, because they mean something very special. They have become part of the community of families and staff involved in our program.

I have tried to give you a flavor of what goes on in such a unit. People often say, "It must be an awfully sad or difficult place." It is not that at all. It has sad moments on occasion, but in general our unit is a place where we find a lot of joy and satisfaction, and especially love.

We like to think that the patients lead the way in showing us how they wish to be treated, especially in terms of our attitudes. It is up to them to show us, as well as family members and the public, how they wish to be treated and how they wish to be regarded. If they wish to be regarded as what we call the "oh you poor dear" syndrome, they will be regarded as "poor dears." If they wish to be treated as normally as possible, and to be regarded as normal by their peers and others, they have to show us the way to do this.

For example, a patient who had been successfully treated for an ovarian tumor had an abdominal scar. When it got hot in the summer, the girls were all wearing their bare midriffs, and she didn't like her scar, so she drew flowers on her abdomen, painting her scar green for a stem. Soon, throughout the entire school, most of the girls had flowers drawn on their abdomens. She had taken her problem and made something enjoyable out of it, something that would be fun. She was leading the way to show her classmates how she wished to be treated, even though she had cancer.

One of the other benefits of such a unit is that the family can really know what has been done and what can be done. If therapy is successful, and the patient does well, it is obviously easy to accept this result. For families of patients who eventually die from their disease, knowing that everyone has done all it is possible to do allows the family to go on living. They know this, not because someone told them, but because they have lived it, and have been a vital part of the care.

The principles described here for children with cancer and their families are pertinent to the care of children everywhere. In fact, I think the principles are pertinent to the care of children with all types of disease, not just children with cancer. These principles probably apply just as well to adults who are ill. What we have to consider is how we provide to each family and each patient the best care for their lifestyle and for the way they wish to live. At the same time everyone must focus their efforts on getting the patient well and the family back to living well again.

2. Panel Discussion: Parents as Professional Members of the Team

Mary Ann Allen
Karen Briscoe
Jeanette Charniak
Genie W. Schweers

MARY ANN ALLEN

I am a volunteer, and I had a child in the 60's who had leukemia for almost 3 years. He died in 1967, and a year later, I went back to the hospital as a playroom volunteer. I wanted very much to make something constructive come out of our experience, so I was able to go back.

I want to share with you a volunteer's point of view:

"The telephone is ringing.
I struggle to awaken . . .to orient myself . . .
The hands of the clock point to 2:30 a.m.
Switching on the light,
I move down the hallway.
In the kitchen, I pick up the phone . . .
"Mary Ann. . .can you come?" says a
voice at the other end.
"The child has gotten much worse.
His mother is upset . . .
We're trying to get in touch with his father.
The child's mother is asking for you."

This telephone call is not unusual. It was made by one of my many friends among the pediatric nurses at the Medical College of Virginia. To me, this phone call in the middle of the night represents the end result of a commitment I have made to myself,

to my patients and their families, and to the staff of my hospital.

Very few hospitals at this point, have developed a paying position for a lay-expeditor on their staffs. However, many pediatric oncology teams might be open to a parent performing this same service on a volunteer basis. By telling you my story, I would like to focus on the many possibilities open to a volunteer in this role.

I have been a volunteer at the Medical College of Virginia in Richmond, since 1968. The year before I began, my son Bobby died of acute lymphoblastic leukemia after having lived with this disease for almost 3 years. Those years of his illness were difficult ones for me and my family. I learned a great deal about the ways of cancer as well as about my own capacities as a person in coming to terms with his illness and death. The experience left me with an intense desire to use what I had learned in a constructive way. To make something good come out of our tragedy.

Because my children were still small, I began as a one-morning-a-week volunteer in the pediatric playroom. Nevertheless, even then, I had some contact with parents of children I knew. In those days the concept of a cancer team was unheard of in our hospital, so my contacts occurred in a haphazard fashion.

As my children grew older, I was able to devote more of my time to work in the hospital. As time went on, I was utilized more and more by the oncology doctors to talk to parents of their newly diagnosed patients. However, when the children left the hospital I generally lost contact with them for long periods of time and only saw them again when the child was readmitted.

Finally about 5 years ago, through the efforts of a patient-counselor-chaplain who was very interested in pediatric cancer, our oncology physicians became convinced of the desirability of a team approach in treating their patients. This team would not only provide medical treatment but would also make counseling available to the child and his family on a long-term basis. I was allowed to join this effort along with the patient counselor. Soon I was given the opportunity to follow our patients in the outpatient clinics and finally, in perhaps the ultimate act of acceptance by the doctors, I was invited to attend daily rounds in the hospital. Not long thereafter, the Medical College of Virginia became the recipient of a cancer rehabilitation grant from the National Institutes of Health, which developed our team concept even further. Its structure reached its present form

with the addition of a chemotherapy nurse and a medical social worker.

It seems fairly obvious that one of the more desirable qualities a parent who wishes to become part of an oncology team can have, is perseverance! Aside from this, any parent wishing to work with an oncology team should have an understanding of the reasons drawing her into this role. In other words: "What do I want to do and why do I want to do it?" This requires a realistic understanding of oneself. "How does all this relate to the concept I have of my own child's illness? Do I have the inner resources to cope with continuing exposure to the grief produced by a diagnosis of childhood cancer?" It would indeed be sad to embark on this type of commitment for all the wrong reasons.

Part of my own commitment has been based on the ideas of availability and continuity. I wanted to try to be available to the parents from the time of the child's diagnosis, onward...with contacts during times of hospitalization and clinic visits, during good and bad times. This included encouraging parents to call me at home if I could be of any assistance and being "on call" at any hour during a child's hospitalization.

As a volunteer, I have been given a great deal of freedom of action to develop my role as I wished. Both the Department of Volunteer Services whose representative I am, and the oncology physicians to whom I am responsible, have allowed this freedom.

Therefore, it was not necessary for me to view my contribution in a daily 9 a.m. - 5 p.m. time frame. This was important for me, since the amount of time I was able to devote to the patients and their families depended on my own home situation. The support of my husband and family has been essential. It takes extraordinary understanding on my children's part when their mother is called away at an inconvenient time, as has occasionally happened.

In addition to self-understanding, there are a number of other qualities that the oncology physicians will be looking for in the selection of a parent-volunteer to complete their team. These include:

- warmth and friendliness -- you will be meeting all kinds of people who are under great stress;
- being a good listener -- allowing patients and their families to express themselves without being judgmental;

- ability to express concern by word, by touch and by presence;
- optimism -- truly convinced of the progress made in childhood cancer in order to support the family's hope for their child;
- discretion and good judgment in conversations with families;
- honesty in dealing with patient, family, and team members -- the only way to inspire trust; and
- willingness to cooperate with the entire team.

In its broader context, the role of an oncology team member can give a parent unique opportunities to learn. Being able to attend in-hospital conferences and going on daily rounds have given me a greater understanding of pediatric cancer in all its forms and has enabled me to better act as a bridge between physician and family.

This role has also given me the opportunity to teach. Panel discussions and talks given to medical students, chaplains, nurses, social workers, and organizations in the community all help others understand what it means to be a parent of a child with cancer.

I have helped organize parent support groups, including discussions on medical topics which contribute to better parent understanding of themselves and of the disease process. For myself, being able to coauthor a booklet on the emotional effects of leukemia on the family has been particularly rewarding. The door is wide open as far as possibilities go for any parent in this role, whether volunteer or paid employee.

For those of you who feel the same desire to use your experiences as I have, please make your wish known to the oncology physicians in your area. What we have to offer them is a very special kind of gift. They have something to learn from us too. We've "been through the fire."

All of you, as parents, understand the need for lay people on the medical team. You understand that only another parent, who is experiencing what you are experiencing, can really relate to you and the kinds of problems you have. It is very difficult sometimes for parents to recognize the kinds of problems that are going on in their lives and the stresses they, their children, and their marriage are placed under: stresses that have to be put in perspective and dealt with while having the overwhelming problem of having a child with cancer; knowing that the child's life perhaps is threatened and not knowing what the next day will bring. It is true that it often takes someone who has been there, or is going through it at the time, to help you do this, but unfortunately, it is not always that easy to sell the medical profession on that idea. So, in case you are all thinking of rushing out and volunteering to be lay expediters, don't get your hopes too high.

The doctors we have here with us today are understanding of these problems and are a very special breed. And, fortunately, all four of us also work with doctors who are willing to let us in, to help them, as well as the families. But that is not true throughout the country. Doctors are very threatened by us, and I can understand that they would be.

The first time I realized this wasn't until I had already been working with them for about 5 years. I was very fortunate. I got into this on the ground floor, way back when there was first starting to be some progress in childhood cancer, when people were beginning for the first time to be aware of the kind of stress this placed on the family, and the problems that were evolving as a result of that stress.

So, the physicians actually came to me. I will say that like Mary Ann, and both Jeanies, I had to start in as a volunteer and kind of edge my way in, and let them learn to trust me, before this happened; but they did come to me with the idea of my working with them as a member of their team, dealing with nonmedical types of problems. It was several years later when I noticed that, whenever I approached a resident or a medical student or sometimes one of our fellows, to report a certain situation that I thought important for him to know, he would jump like I had scolded him or criticized him, and would immediately become defensive. You know I didn't realize they were afraid of me, because I am one of those people who always put the doctor just a little bit lower than God. There is no way I would scold a doctor. I trembled when one spoke to me.

So, I finally had to become aware of that problem and work on it. I also found that you do have to use a lot of tact, be very gentle, and prove your trustworthiness to physicians.

We have a team now, a rather large core team, and fortunately when our doctors mention the core team, I am included. I sit in on all of the staff meetings and in most of the decision-making, and I appreciate that very much. They come to me with their ideas and concepts of what families might need and what might be helpful. They use me to validate their theories.

We have a unit similar to that which Dr. Wilbur has just explained. I was very excited to hear his speech and to realize that that is going on across the country. I think the most help parents can get, is still from each other. When you put the children all together on one floor, and you allow the whole family to be involved, then everyone, siblings, parents and children, will receive the kinds of support they need--ongoing support.

Where I work, it is a large medical center, and people come from hundreds and hundreds of miles away. Currently, there are over 500 patients and their families that I am following. We make it a practice to follow families with letters and phone calls for a minimum of 2 years post-death, because there are a lot of problems that happen after the child dies that you need to pick up on, and you really can help the families reintegrate back into as normal a life as possible. So, there is no way I could give the kind of support I did in my original role, back when we had 40 patients, which was basically one of handholding and giving support. Therefore, it is much more feasible to help a family to meet someone else, whose circumstances are as identical to their own as possible, and then to let them continue the support.

Families who, for instance, live 400 miles away will perhaps have someone 30 miles away who is either going through, or has been through, a similar experience, whom they can call on for help, in addition to the team at the medical center. A large part of my job has evolved into being a coordinator; getting parents together, and providing programs where they will meet and have contact with one another, so that they can give each other this type of support.

JEANETTE CHARNIAK

To describe the makeup of cancer care for children in our area, I will speak about our Group, cancer teams, clinic care, about the Green Bay area, and about the parent consultant part of the team. I represent the Parents' Group of Children with Cancer, first organized in March 1974. Our Hematologist-Oncologist treating the cancer child in Green Bay, N. W. Wisconsin, and the surrounding areas, is Stuart Adair. In addition, his cancer practice is connected with a major university research center. Major treatment is usually carried out at this center, the Milwaukee Children's Hospital, while routine checks, blood work, bone marrow, L.P.'s, chemotherapy, and well-child care is done at Webster Clinic.

Green Bay has a population of about 100,000, about 160 miles from Milwaukee and Madison. Our area is fortunate to have excellent medical care, which means less time away from home and fewer long trips: a plus in the total care of the family.

The Parents' Group of Children with Cancer has successfully continued for 4 years, serving about 28 families of cancer children, and 14 families whose children have already died. Not wishing to go into all the excellent monthly meetings, speakers, and special events, I'll say a few words about the makeup of people, and advantages of a small city group. We experience a closeness that few other groups can share. There's a spontaneity of self-oriented energy; action of its very own without restraints.

The parents are quick to respond, to support, to help in the hospital or clinic. Clinic day sees many parents meeting and talking, children playing together, becoming close. Later on, contact continues through phone calls or small get-togethers.

I find my role as parent-consultant unique. It's being a pioneer in having the medical profession accept a lay person in the treatment or care given the cancer child and family. It's being part of a motivated smaller team, which tries to meet the multi-dimensional needs of the chronically ill child and his family, from diagnosis, through remissions, or death, and after. Families benefit from relating to the parent-consultant as a more understanding peer, because she has had the intimate experience of having a child go through the illness, and death. There is an acute power of observation, sensitivity to the needs of the parents, and the capacity for taking time.

Lay people working with the professional team come in contact

with problems, so we must know ourselves well, where the gut feelings are. We find we experience the threat of death many times and really no matter how we think we are prepared, there will still be fear when we ourselves must face death.

In addition to helping parents, we receive many unseen benefits. We learn, and we feel useful and important. We see the power of healing, of people being relieved from fears, feeling the security of the caring people surrounding them. Their own values, and the strength and unity of the family are maintained for this most difficult task.

We try to understand suffering. Somehow the patient and families must learn to endure suffering because we are human and it's a basic part of life. Individuals better able to cope with this new life style, new stresses, are probably people who have lived through difficult decisions and problems before. They have high personal values, for themselves and for others, and they have self-confidence. Families must understand that cancer is usually a fatal illness, involving remissions, relapes, complications, cures, or moving toward a terminal state. There will be losses and they must learn that to give up something is to find LIFE.

The parent-consultant is introduced to the family shortly after diagnosis. Parents need to understand and manage their child's illness, and they must help the child to cope with his illness. In the meantime, they must also continue to meet the needs of all the members of the family. Parents find that their former patterns of coping with stresses become inadequate, so the ability to change and adapt become important. To accomplish these basic duties, parents must have trust in the medical profession and in themselves. They need information about the disease, for it will affect the whole family; guidance and support, resources to cope with the crisis, both personal and financial. Parents are relieved to know that others have experienced the same feelings and frustrations and were able to move on from one stable period to another.

Parents are introduced to each other usually at the clinic, and they share information about chemotherapy protocols. They identify their child with the others including the progresses or relapses. They are able to see that sickness is not a state of being useless or as a punishment, but that it can be a very positive role. So these children are able to see a new and profound meaning to life, to accept pain, to be joyful, to come face to face with what we really are, to live life to the fullest, and to be a source of strength to those around them.

After the initial phase of diagnosis and shock, denial of the disease is usually transferred to a feeling of helplessness, the child is doing well but the threat of relapses is always present. Hostility and anger is shown toward the medical personnel. At this time they discuss more intense issues such as: How will we get through this? Can we be normal again? Will the siblings develop problems? How to handle them? What is our role in the community? How do we communicate to the relatives?

During relapses, more questions on death come forward. Hope remains but they are preparing for death through coping and by grieving. Grieving is surprising and strange. It requires great love. Questions are asked about dealing with the practical sides of death, the funeral, and the understanding of one's grief processes is shared by others.

Contact is maintained with the family after death. They are not left to deal with the added physical and emotional strain alone, but are encouraged to find positive solutions for all these issues. Parents will not get out of the grieving situation unless they really want to, unless they can form new goals and are ready to enjoy life.

The parent-consultant during these stages is usually available at the clinic to speak with the parents, make them feel comfortable, and help the children find friends. Introductions to the other parents sometimes establishes long friendships. The parent-consultant listens, is a trusted friend, and relates problems to the medical staff. Home visits when the child is no longer able to come to the clinic, are also a function of the parent-consultant. Phone contact is made with out-of-town families, to identify any problems that they may not wish to bother the professionals with.

Support is given to the dying child and family. If a parent-consultant establishes a bond, it must be continued throughout the illness. It's important to understand that this person cannot be all things to all people. Sometimes it's impossible for her to be such a contact person. If that happens, she must allow the closer person to have the same freedom in care, even if it means her supporting the one who supports. Volunteer help in all areas must be used to its fullest.

The lay person is also instrumental in obtaining transportation funds for the parents, dressings or equipment needed for home care. She may also be called upon to explain the purpose of the group or her position to the community.

These are the qualifications for a parent-consultant as a team member:

1. Actual personal experience with illness and the death of a child;

2. Intellectual interest in the disease, ability to gain knowledge, and the determination to seek it;

3. Openness to others--ability to recognize, respect, and accept all people, ability to listen, and have time to be open;

4. Ability to communicate with people, work as team member, and follow the directions of team members;

5. Personal maturity;

6. A stable home life and a variety of outside interests;

7. An intense depth of feeling and concern for patient and family;

8. Ability to work independently and to be responsible for one's own actions;

9. Ability to understand one's own feelings and values about death;

10. Knowledge that the family needs are the ones to be met -- they are not us, their children are not ours, and if we assume that they are, then we become the receivers and their needs are not met; and

11. Ability and courage to give of oneself.

A mutually supportive group working together is necessary. The team works best when the primary physician has the ultimate responsibility for matters relating to patient care and the family. The physician is the resource person and must utilize the proper blend of staff for the patient. No one person has all the answers. Listening and sharing and deep concern will be of invaluable help to the child and family. As the parent-consultant learns, she develops self-confidence, she acquires the ability to recognize individuals as unique; to spot personality styles; and to acquire a certain expertise through regular exposure to all phases of care management. It's a challenging position. A reward of life.

The following is a beautiful passage:

"God has given us everything we need for life, we must use our talents, gifts, to the utmost, in the role as care giver we can be an important instrument of God by adding

Goodness -- to the faith we have

Understanding -- to our goodness

Self-Control -- to understanding

Patience -- to our self-control

True Devotion -- to patience

Kindness toward our fellow man --

To Devotion and to this Kindness --

LOVE"

If we have a generous supply of these gifts, we won't be ineffective. We have been chosen because of these very qualities and must work all the harder to justify them.

GENIE SCHWEERS

One of the things we want to share with you is the unique way in which each of us got involved in our work. Perhaps it will enable some of you to see some holes in your system that you can plug in to and help out in the way we do.

My daughter was diagnosed 11 years ago with ALL. We are an 11-year-old success story. However, there have been three relapses, so we have been in treatment most of that time. Several years ago, when Dr. Forman came to our hospital, there was an inter-hospital seminar on acute leukemia, and he asked if I would like to come and share the parent's perspective. While I was there, I discovered that although the talk was very scientific, and I didn't understand all the words, I certainly did understand the meaning.

Upon going home from that meeting, I wrote a letter asking that written information be developed for parents, and got a very nice thank you. One and a half years later, when nothing had beer.

done, I decided it was time to do something. I wrote an outline and over the next 2 years sat with the physicians and other members of our hospital staff to develop the handbook. It is now being published by the American Cancer Society, and will be available to all of you through the local divisions.

That handbook discussion made us all realize that we had a lot to learn from each other, and we developed mutual trust and respect. I began to volunteer my time at the hospital to talk from the parent perspective about what was going on in cancer care. After some time of this, I came in one day and said, "I am tired of being paid by someone else to work here; I don't like being paid by another employer and giving myself to this job, so please find a way to pay me." That was in May.

Funding was sought from a private grant through the head of our oncology department, Dr. Louis A. Leone. However, by June, nothing had happened, so I finally said, "I am coming to work August 1st." On August 15th, I began receiving a paycheck for half-time work. Two years later I needed to be involved in a full-time work situation. I again went and proposed this, also stating my need for hospital employee status and Blue Cross coverage. This year, I have been on a four-part salary; one part from medical oncology, one part from pediatrics, one part from the American Cancer Society, and one part from special pediatric-oncology funds.

As of October of this year, I will be a full staff member and the hospital will be paying my total salary, and I think that bespeaks the hospital's appreciation of how a parent can help and what a boon that kind of person can be to the hospital process, as well as to families.

3. Parental Interrelationships in Living with Pediatric Cancer

Gary Morrow, Ph.D.

Much has been written on dying from cancer. From an avalanche of scholarly tomes to the latest headline in the National Enquirer, there seems, at times, to have been an almost daily equating of cancer with dying. Some have suggested that "death and dying" has perhaps been studied and talked to death and deserves to die. This suggestion has some merit, for there needs to be a shift in emphasis to another type of experience with cancer. Ever increasing numbers of persons are living with cancer. Little is known about their adjustment and what types of assistance may be most helpful for aiding their adjustment and coping with cancer. However, we're beginning to systematically try to learn more.

The first step in our learning is to understand the major problem areas of long-term difficulty. Before designing and trying approaches to aid adjustment to difficulties, it is necessary to know clearly what those difficulties are.

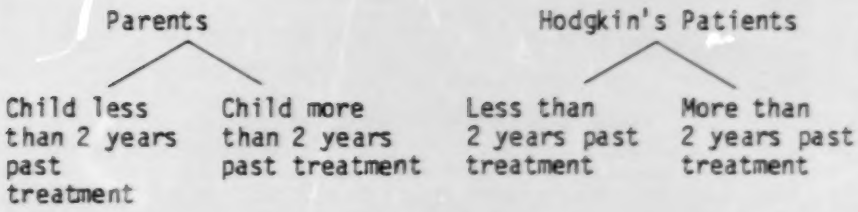
The purposes of this presentation are: (1) to present and discuss preliminary results of our studies on the long-term adjustment of parents whose children have cancer, (2) to compare these results with those of long-term Hodgkin's disease patients, and (3) to present and discuss areas where husbands and wives may differ in the potential impact their child's cancer experience has on them.

Description of the Study

Figure 1 outlines the groups of persons who have participated in the study thus far. The two basic groups, parents and Hodgkin's patients, have been divided further into two subgroups: those less than 2 years past treatment and those more than 2 years. The 2-year point was a somewhat arbitrary dividing line for separating patients and parents who were felt to be adjusting to issues of living with cancer after a 2-year disease-free interval.

FIGURE 1

PERSONS PARTICIPATING


Parents
Hodgkin's Patients
Child less than 2 years past treatment
Child more than 2 years past treatment
Less than 2 years past treatment
More than 2 years past treatment

Twenty-eight parents whose children (ages 15 months to 18 years when diagnosed) were more than 2 years past a single treatment for Hodgkin's or a solid tumor, participated in the study. Their children were an average of 5.5 years post-treatment. An additional nine parents whose children were less than 2 years past treatment have also been studied so far.

A comparison group of 32 young adult Hodgkin's patients who were more than 2 years past treatment (average of 5.8 years) have also participated. An additional five Hodgkin's patients who are less than 2 years past treatment have been studied so far.

Types of Information Obtained

After their child's physician (or in the case of the Hodgkin's patient--their physician) had given his permission, the parents were contacted and, if they agreed to participate, an interview

was set up in their home. The semi-structured interview included items from the Psychosocial Adjustment to Illness Scale (Derogatis, 1976; Morrow et al., 1978). A 5-minute verbal sample was tape recorded and analyzed for affective dimensions such as anxiety and hostility by using the method of Gottschalk et al., 1969. A questionnaire containing further questions on parental attitudes was left behind after the interview to be filled out and mailed back.

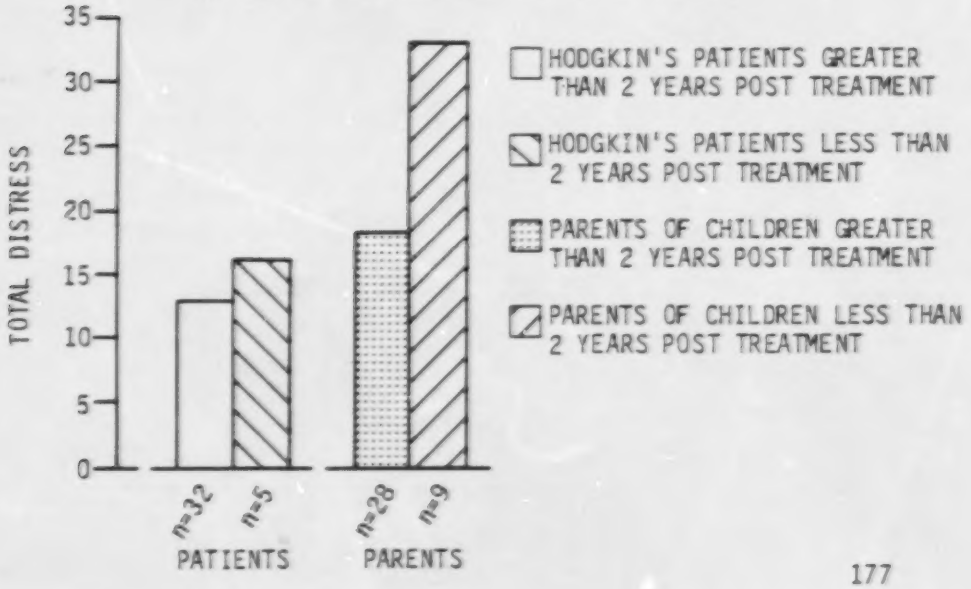
Data were coded and analyzed without including any names so that confidentiality was maintained. Responses of parents were compared to those of patients in addition to comparing responses of husbands and wives.

Psychosocial Adjustment of Parents Compared with Hodgkin's Patients

Figure 2 shows total pyschosocial distress scores for both parents and patients. Both the patients' and parents' groups have been divided into those less than 2 years past treatment and those more than 2 years past treatment. In general, the parents were found to be experiencing greater distress than the Hodgkin's patients.

FIGURE 2

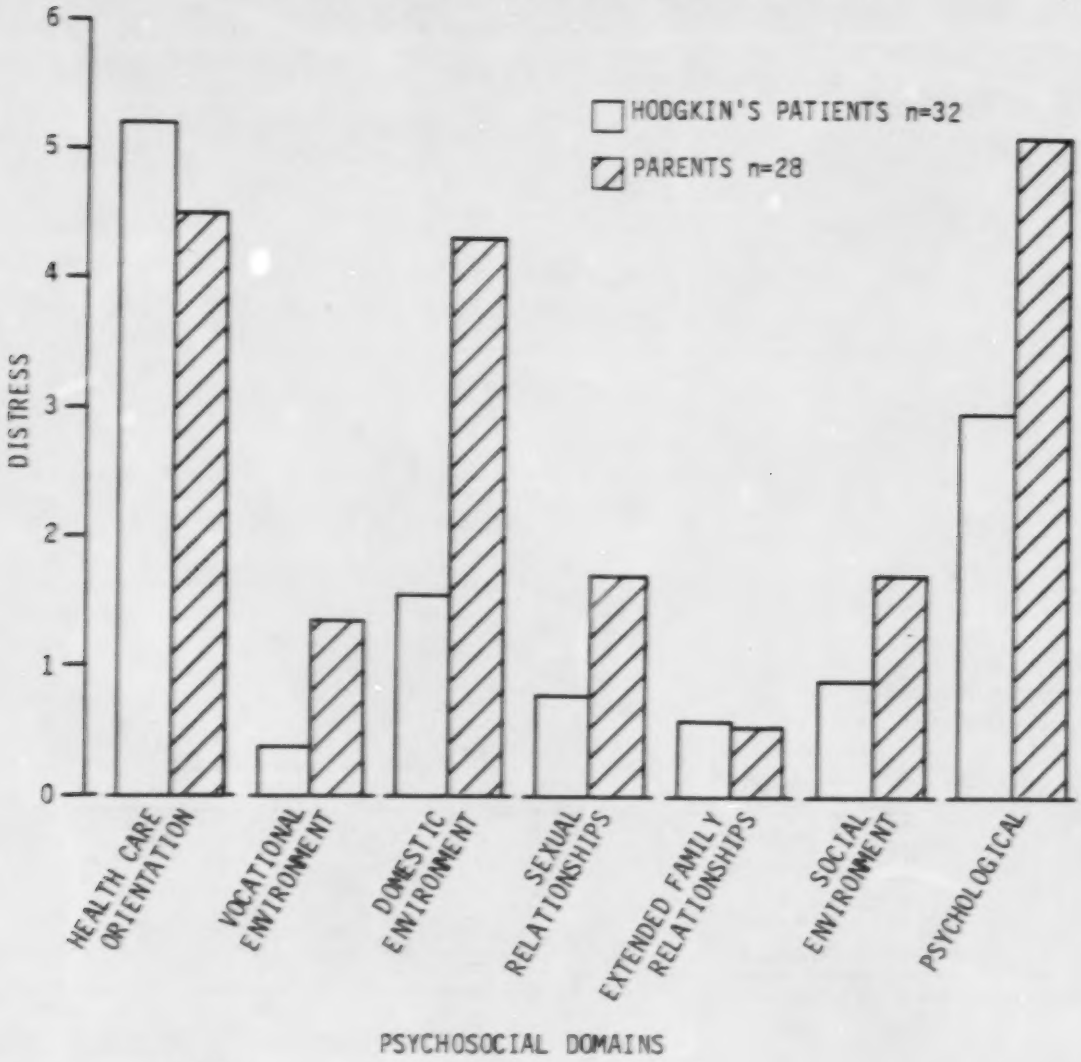
PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE
(PAIS) TOTAL DISTRESS SCORES BY GROUPS



Parents whose children were more than 2 years post-treatment for Hodgkin's or solid tumor were found to be experiencing significantly greater total psychosocial distress than were a group of Hodgkin's patients more than 2 years post-treatment ($t=2.98$, $p<.01$). Analysis of individual areas of adjustment (or domains) showed the parents to be experiencing greater distress than patients in several of the areas shown in Figure 3.

FIGURE 3

COMPARISON OF HODGKIN'S PATIENTS' AND PARENTS' PSYCHOSOCIAL DISTRESS IN SPECIFIC PAIS DOMAINS



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Specific Areas of Greater Parental Distress

The parents were found to be experiencing greater distress in their vocational environment ($t=2.54$, $p<.01$). Parents reported their child's illness had affected such things as how they evaluate their present job performance, time lost on the job, changes in their vocational investment and the goals they have set themselves, and interpersonal conflicts that they have been experiencing within their work situation.

A second specific area where parents were found to be experiencing significantly greater distress than Hodgkin's patients was that of their domestic environment ($t=2.08$, $p<.05$). This area assesses illness-induced difficulties that arise primarily in the home or the usual family environment. Among the items assessed are the quality of the relationship with others living in the home, the degree to which the family has adapted to the illness and possible changes in their communication pattern and style, the changes in the dependency relationship they have with other persons outside the family, potential physical disability, and the impact illness has had on a family's financial resources.

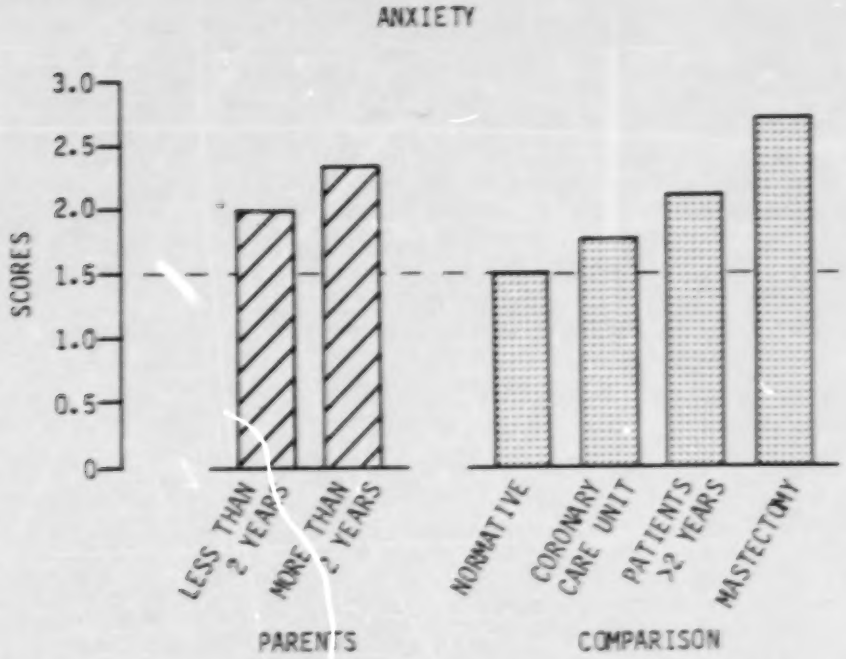
The parents reported significantly greater psychological distress than the patients ($t=2.31$, $p<.05$). Major dimensions of psychological functioning and affective responses assessed included anxiety, depression, guilt, hostility, worry, self-evaluation, and negative body image.

Parental Anxiety

In addition to the psychosocial aspects of problem identification examined in the previous results, a portion of the study dealt with the affective responses of the parents group. Figure 4 presents a graphic summary of the anxiety expressed during the interviews with the parents' group. The first bar to the left is the expressed anxiety of parents whose children were less than 2 years out of treatment while the second bar to the left shows the expressed anxiety of parents whose childen were more than 2 years past their single treatment. The four bars to the right of the Figure are included for comparison purposes. They are results from four other groups of people: (1) a normative group from the general population whose score of 1.5 is considered the average score for the instrument (Gottschalk, 1969), (2) patients recovering from a heart attack in a coronary unit (Leigh et al., 1972), (3) Hodgkin's patients who are more than 2 years past their single treatment for disease, (4) recent mastectomy

patients (Holland, 1976).

FIGURE 4



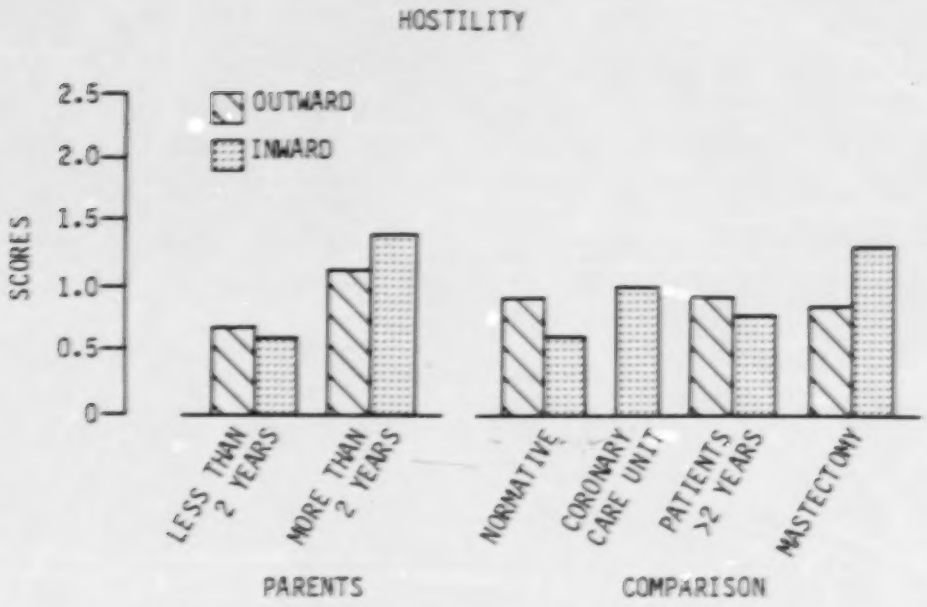
As can be seen from Figure 4, parents whose children were more than 2 years past treatment were expressing greater anxiety than those whose children were less than 2 years past treatment. Both parents' groups were found to be more anxious than either the normative sample or the sample of heart attack patients recovering in a coronary care unit. Their anxiety scores were similar to those of a group of young adult Hodgkin's patients who were beyond 2 years post-treatment and less than those of a group of recent mastectomy patients.

Parental Hostility

Figure 5 presents results for the parents' group and the four comparison groups in terms of expressed hostility. This effect was studied for several reasons. Hostility is an affect that is frequently reported clinically not only by treating staff but

also by users of the health system. It is an important element within interpersonal communications, and has been frequently cited in the literature as a normal reaction of persons associated with worry and concerns in difficult situations. (Lascari and Stehbens, 1973). There are two dimensions of hostility shown in Figure 5. Hostility outward, shown by the solid line, is expressed hostility, usually directed at others. A second dimension of hostility shown is that of hostility inward. This is hostility turned toward the self, anger which is directed at oneself as opposed to being expressed outwardly at others. Hostility inward is an affect closely related to depression. The balance between hostility directed outward and hostility directed inward may provide information on ways in which adjustment is being handled.

FIGURE 5



As with the previous figure, results from the group of parents whose children are less than 2 years past their single treatment, and the group of parents whose children are more than 2 years past their single treatment are shown to the left. The four comparison groups previously described are shown to the right of the figure.

The groups of parents whose children were less than 2 years past treatment were showing somewhat less outwardly directed hostility and about the same degree of inwardly directed hostility as the normative sample. The hostility measures of parents whose children were more than 2 years past treatment are elevated above that of the parents whose children were less than 2 years past treatment. It is interesting to note that the parents whose children were more than 2 years past treatment were expressing greater inwardly directed hostility (depression or hostility turned towards the self) than parents whose children were less than 2 years past treatment.

One implication of these findings is that parents whose children were more than 2 years past treatment appeared to have an increased tendency to direct some of their anger and feelings of hostility towards themselves than towards others in their environment.

Differences in Adjustment Between Husbands and Wives

There were no significant differences found between husbands and wives within the group of parents whose children were more than 2 years past treatment in terms of either anxiety or inwardly directed hostility. Husbands, more than wives, were found to express significantly greater outward hostility or anger towards others and their surroundings. Husbands whose children were more than 2 years past treatment reported that their child's illness had a significantly greater effect on their work and their current health than on their wives.

Wives, on the other hand, indicated that they perceived their child's illness as having a greater effect on their general level of activity than on their husbands. They expressed, however, a greater degree of optimism than their husbands did towards the future, and were also generally more positive about the care that their physician had given their child during treatment.

Discussion

What then is there to make of these results? The first important point is that these results need to be interpreted with a marked degree of caution. The total group of parents who have been studied thus far is not large. The group of parents whose children were less than 2 years past single treatment is quite small, and it would be a mistake to place a great deal of confidence in the stability of their results. At the present time, any results from the sample of parents whose children are less than 2 years past treatment must be considered as tentative. The results may be seen as suggestive of certain trends, perhaps even a beginning foundation, upon which to construct a more careful profile of the specific difficulties for which help may be designed, but little more. With these cautions in mind, it is possible to begin constructing a tentative picture of what our studies are showing. What is emerging is a pencil sketch that does not capture the richness and fullness of an experience requiring an oil portrait to capture individual differences. But it is a beginning.

It is of interest that the group of parents was experiencing greater total psychosocial distress than a group of patients with cancer themselves. This finding supported our clinical impression as well as that of others.

The elevated scores of parents within specific areas of distress, most notably vocational environment, domestic environment, and psychological distress, is a beginning towards the identification of specific problem areas so that greater attention can be paid to these.

The fact that distress was still being shown an average of 5 years past treatment, however, indicates the need not only for long-term followup and involvement with parents whose children had been treated, but also may indicate why groups such as the Candlelighters and other self-help groups have been formed.

There were few significant differences expressed between husbands and wives in terms of specific problem areas. Husbands reported a greater disruption in their work while wives expressed a greater disruption in terms of their general activity. Interview findings from the study support the often-reported notion that a large measure of the responsibility for the care of an ill child appears to fall disproportionately upon wives as opposed to husbands (Binger et al., 1969).

Parents whose children were more than 2 years past treatment were

found to be more anxious than parents whose children were less than 2 years. This may indicate that fears and uncertainties increase over time. More intensive followup and reassurance by health care providers beyond the period of active treatment might be helpful.

The hostility measures indicated that, generally, the groups of parents whose children were more than 2 years past treatment were significantly elevated above that of a group of parents whose children were less than 2 years past treatment. Just as anxiety appears to increase with time of survival and cure, so does hostility increase with uncertainty over the future. It may be important for parents to recognize that their often intense focus of concern over an ill child can affect different aspects of each other's lives as well as their interrelationship! Husbands and wives are an important source of support and strength for each other. Taking special time for each other--time to talk, time to share, time to care--can be a way to reduce problems.

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4. Questions and Answers

[MS. ROBINSON]: My name is Susan Robinson. I am from Canada, and have a little different perspective, I guess, from most people here. We have a center in Edmonton, Alberta, very much like Dr. Wilbur's, not as advanced in some of the medical involvement.

I am sure that if I wanted to get involved in that sort of thing, injecting the IV's, for example, the health professionals would be willing to listen to me. I have total faith in our health care system.

After my child had been in the hospital, I wrote copious letters to the nurses, and told them exactly how I felt. I think that is something we have to do as parents. They have self-doubts whether they are doing the right thing as we do. I think they need our support as much as we need theirs.

[MS. EDDY]: I am Edwina Eddy, from Montreal, Canada. We have a very good health team in Montreal Children's Hospital. One of the things that fascinated me was that you had stoves, refrigerators, and all kinds of things. I was allowed to stay with my son at all times and slept with him until he died. How is this funded?

[DR. WILBUR]: I really don't think that funding is the major problem. I think it is having the administration of the hospital feel they can allow you to do your own thing. After all, if you were a parents' group and wanted a refrigerator, you could figure

out how to get a refrigerator. Our hospital funds our facility because they believe in what we are doing.

[MR. CHASSE]: Remember, you are the consumer, and the consumer has the right to dictate how the services he is receiving are to be given.

[MR. STURM]: I am Lee Sturm, from St. Louis. I have two remarks, maybe just observations, concerning the presentations that were given. They covered such a wide gamut of the emotions, the feelings, and experiences we all have. Two things came to mind during these presentations. One relates to the emotional support the parent needs to give the child. My wife made a shrewd observation a couple of months ago at one of our local meetings, and it related to the fact that the child, prior to treatment is frequently upset and distressed. In my ethic, in my background, I have always said, "It will be over, be brave, brace yourself, be strong, don't cry." And I can recall several occasions where she chose to cry with him, share his grief and anxieties, and I think that is an important aspect of being parents. I was, I guess, never able to bridge that. I always wanted him to be strong, to be a man. You know, he was 7 years old, and she chose to cry with him, to share his hurt and grief. I think that is one role we can all improve on, to share the grief with the child, because it is tragic.

We have all talked about helping each other, and this is the other aspect that I would like to develop. In our hospital, in our team panel set up yesterday I am sure all of you were aware that there was a young nun who had an extraordinary rapport with small children. She is an integral part of our health care team, and her help does not have to be religious. She is what they call a patient-relations specialist. She is trained in her field, but she offers these children an opportunity to talk to someone, other than family and doctors, about all kinds of things. Children confide in her. The point of my comment is that children need a counselor, someone in whom they can have confidence and trust, and someone who is willing to listen, and maybe develop their thoughts about how they feel about themselves and their illness.

[MR. de LAURIER]: The first question is for Genie Schweers. We talked a little bit about the handholding aspects of the lay expediter or the parent representative. How do parents on the team get involved in patient rights and advocacy issues?

[MS. SCHWEERS]: Yes, I do a lot of that, and I would like to take the question in two parts. I think each parent should

become an advocate for his child so the child gets all necessary medical or emotional care. I am a parent myself with no special background. By being a professional member of the team, parents learn to become more willing to pick up the advocacy issues for themselves and their own children.

I also sit on many hospital committees as an advocate for all patients, so that advocacy issues or patients' rights do not get lost in the process. I think that all of us can pick this up, and I appreciate very much what Dr. Wilbur had to say. It is not the funding that is the problem. Often, it is the attitudes that have to be changed. One of the things I do is maintain a parent's perspective, but I have hospital status, so there are many things I can do as a parent to change what goes on. I have been known to ask doctors to stop arguing about who is going to do a spinal tap and get it done because it is more important for the child and parents to have the care they need, than for medical residents to get practice.

I know those kinds of things are not always popular to hear, but that is what I do to try to keep the system honest.

[MS. MARIOLES]: I am Yolanda Marioles, from San Antonio, Texas. We have a cancer research treatment center similar to Dr. Wilbur's in theory. It doesn't always carry over from the clinic to the hospital, but the parents have tried to carry it over with the blessings from our doctor. Little by little we have indoctrinated the nurses and social workers, so now the hospital is sitting up and looking at us. The greatest lesson I have learned as a parent of a child with cancer was that I had a great fear. It took me 6 months to say the word "cancer," and it was so ugly. I think it was because I didn't know what cancer was, and learning to treat my child, I learned what cancer was and to conquer my fear.

Then I wasn't afraid to see her die. And if it happened to me again--I wouldn't wish it for the world--but I think I would not have that black fear again. It will never be the same, and it came from learning, from all the doctors, nurses, and social workers.

[MR. de LAURIER]: How do you take care of your own personal emotional needs when you are constantly reliving that experience during your care for other people? Do you find that families are eager to work with you, join a group, or do they just want to ignore you?

[MS. ALLEN]: When you have a close team relationship, it helps a

great deal. When you get "down," you have to know how much you can take. You also know that you can get out of that depression, and with good team support, your team will take care of you.

[MS. SCHWEERS]: Do all parents want to relate to you?

[MS. ALLEN]: I know that I cannot relate to each parent. When a child is first diagnosed, some parents know that I have lost a child, and get completely turned off. When I first encountered it, I was hurt, because it was not my fault that my child died. But you learn to deal with that, and other members of the team can step in.

[MS. SCHWEERS]: I get support from a number of sources. My daughter helps to keep me honest. She doesn't let me get away with much, and she hits me with a lot of hard questions. When a child dies and I am feeling bad, I need to tell her, because I usually go to children's funerals. If she knows I am going to a funeral, she wants to know whose it is. We talk about the fact that the child died, and it brings up the fact that she might die. It also brings up her guilt that she is alive, and so many other children have died, which is another facet to be faced by long-term survivors.

Another big source of support for me is the parents I work with. Many people say to me, "My God, you do this all day and then you have to face it at home 24 hours. How do you cope?" It is not hard at all. One of the teenagers put it very well yesterday when she said that what she shares with other people gives her support. My daughter relapsed after 5 years this January. Our unit had a family at Johns Hopkins whose child was in the midst of undergoing bone marrow transplant. That mother heard about Fredrika's relapse, and called me (in Rhode Island) to offer support. I also have support from professionals, but I wouldn't trade my parent supporters for anyone.

[MR. de LAURIER]: We have a few questions for Mary Ann Allen: What are your limitations?

[MS. ALLEN]: I have discovered and accepted the fact that I will not be able to have a good relationship with every family. I have found that time prevents me from doing some of the things I would like to do in counseling and writing.

[MR. de LAURIER]: Where have you made mistakes?

[MS. ALLEN]: Perhaps the greatest difficulty I have encountered is meeting new families. I am essentially a shy person, so my

initial interviews with new families is not an easy time for me. However, once a common ground has been established, I have been able to overcome the initial uneasiness. I guess I'm trying to point out that shyness need not keep an interested parent from assuming the role of lay expeditor.

[MR. de LAURIER]: Do you find that families whose children were recently diagnosed were anxious to join a group, or do you find that these parents needed to talk to someone on a more personal, one-to-one basis?

[MS. ALLEN]: This is a difficult question to answer. We routinely inform our new families of the existence of our two parent groups (one in Richmond and the other in the Tidewater area of Virginia). Many parents are interested but are never able to attend because of the distances involved. We also offer families who seem interested the opportunity to meet the parents of long-term patients with the same diagnosis. We often give them the names of families in their own area whom they can contact on their return home after their child's initial hospitalization. There are, of course, some parents who are turned off by all of this and just want to be left alone and we respect this.

[MR. de LAURIER]: Do any of the parents on the team get involved in patient rights and advocacy issues?

[MS. ALLEN]: I became involved in this area only in an informal way. My hospital has a formal policy on patient rights already. But sometimes in conversations with parents, I find that they are not aware of some of their rights. In these instances I try to help them in understanding what they are.

[MR. de LAURIER]: How do you take care of your emotional needs?

[MS. ALLEN]: I have to accept the fact that I will become depressed and discouraged at times, that sometimes I will have to step back from involvement. I find a great deal of support within my team and I have a close relationship with them. These things, in addition to time off, outside activities, and the knowledge that I have helped many families have given me the desire to continue.

My emotional needs are met by the medical team, in talking with our primary physician and the nurses. However, this has never been a large problem for me. I am better able to give support to the parents because I have come through the process a better, stronger person, with the correct ideas and attitudes about

illness, living, dying, and suffering. It's not the parent of child who tests my emotions but the thoughtlessness of other people.

[MR. de LAURIER]: A question for Mrs. Charniak: What are your limitations?

[MS. CHARNIAK]: I use common sense and good judgment as to how far to carry a problem or a request. But going to the correct person to handle the situation is usually sufficient. Also by approaching the top person, my viewpoint is considered and usually accepted. Actually, no limitations have been put on me.

[MR. de LAURIER]: Where have you made mistakes and/or had difficulties?

[MS. CHARNIAK]: In convincing some professionals that an intelligent, caring lay person can be instrumental in providing support and psychological care, time that they cannot sometimes give. At times they felt threatened by my going ahead with an idea or following up on a problem or situation. This feeling of being threatened is lessening.

[MR. de LAURIER]: Do any of the parents on the team get involved in patient rights and advocacy issues?

[MS. CHARNIAK]: No patient-rights or advocacy problems have come up. Our primary physician, Stuart Adair, M.D., is responsible for the excellent rapport with the families, as well as instructing and educating the patient.

[Q]: Dr. Morrow, can you comment on the divorce rate of parents whose children have cancer?

[DR. MORROW]: We have no direct data on divorce in the group of parents whose children have cancer. The impression from the few independent studies done previously, as well as the more complete recent Candlelighters' survey is, however, one of a rate somewhat below the national average.

If anyone, by the way, has seen any particular figures done systematically, I would like to know about them, because we ourselves were unable to find a well-documented study.

[MS. BRISCOE]: We conducted a study on the divorce rate at the Mid-America Cancer Center about 2 or 3 years ago, and we have the data for that. I can't give you the exact percentage, but you are correct, the divorce rate was lower than the national aver-

age. These figures have been published. So, if you will write to me, we can give them to you.

[AUDIENCE COMMENT]: That is more recent data. There is a series of older studies by Al Canen at the College of Michigan adjusting the rate anywhere from 50 to 75 percent in a 2- to 5-year span, particularly following the death of a child. But there are differences prescribed, and the numbers are there.

[AUDIENCE COMMENT]: One of the earlier studies by David Caplan at Stanford University is the one used frequently to quote higher divorce rates.

[AUDIENCE COMMENT]: We have the Candlelighters' questionnaire of 156 respondents. There were 9 who had a change in marital status, just as an example.

[MS. BRISCOE]: I think the point about studies done at different times and with different groups is an important one. We took a random sample, so it should cover all areas, but I also like to think that our studies may have been affected by the intervention of the team during the last few years.

So, I think any information we can get on earlier studies should be compared to studies where there is some intervention and some dealing with the emotional needs of families. Then it would be interesting to see if that affects the divorce rate. We are hoping it would.

[Q]: There are two questions for Dr. Morrow which can be combined: How have parents dealt with depression? And what happens if you cannot get one of the parents to face the fact that their child is ill with a life-threatening disease?

[DR. MORROW]: One of the things that is difficult about presenting preliminary results at a conference is that you don't have all of the answers. We don't have yet a systematic look at how various people have been addressing the difficulties. This group of parents we studied was not affiliated with the self-help parents group in the area. Some of the people had sought professional help. Some had sought support through neighbors and church groups. And a good number reported that their spouse was not only their best friend but also the greatest source of support that they had. Beyond this finding we have no systematically gathered information at the present time.

[Q]: How have parents found a way to deal with depression due to illness?

[DR. MORROW]: Depression, along with anxiety, anger, hostility, joy, hope, and a variety of other emotions is a normal part of life and living. We all experience these emotions from time to time. In situations such as major illness, they may be expected to not only be more intense but also of longer duration. Support from spouse, family, and significant others can be important in dealing with the often brief episodes of depression occurring as a reaction to loss or change in treatment course or prognosis. More prolonged episodes involving loss of appetite or sexual interest, or marked disturbances in sleeping, or thoughts of suicide should be discussed with a family physician, clinical psychologist, or psychiatrist. In such cases medication is often a very useful aid to psychological treatment.

Following the presentation, several parents were kind enough to share their experiences with me. It was interesting that some had experienced severe depression not immediately after their child's death, but rather when friends and family appeared to reduce their support and concern many months later.

[Q]: How would you get parents together when one parent refuses to face facts and the other one wants to talk about it?

[DR. MORROW]: It's important to keep in mind that there is no one best way to handle stress and the psychological consequences of a major life disruption such as cancer. Different people handle such events in different ways--those they have found adaptive in the past. Denial, or refusing to face something difficult is one very common initial reaction.

For those who say, "It's not there. I don't have to recognize it and deal with the pain, fear, and other feelings it will bring," denial can be adaptive by protecting a person from being overwhelmed by feelings.

An initial reaction of refusing to face an event such as a cancer diagnosis in a child may be expected of some people as a normal reaction. This is as necessary to keep some people's equilibrium as wanting to talk about it is to other people. Denial usually decreases as the person becomes more able, with time, to accept parts of the problem without feeling overwhelmed. For the majority of such people, the refusal to face is of relatively short duration. Their need initially to deny should be respected as much as others need to talk it out.

When, however, denial continues beyond an initial reaction, some attention should be directed towards its resolution. Parents need to share their feelings and how they are coping with each

other. Groups such as the Candlelighters can be of great help in providing the atmosphere where support and sharing can take place not only between spouses but others. One person sharing an experience of "I know how you feel, because I've been there, afraid to face it myself" with another is of great benefit. Another potentially useful approach is for the spouse troubled by the other's continued denial to bring up the denial and inability (not refusal) to deal comfortably with the situation. Together they can explore whether they can deal with problems better together than either spouse can do alone.

X. Practical Problems

1. Discipline and Training

Richard H. Lucas, Ph.D.

Children learn from us. We take this simple fact and often jumble it around or over-psychologize it to the point where we confuse our children. In conferences about children with cancer, we frequently ask: "What do we know about the children?" We seldom ask the more important psychological question: "What do the children know about us?"

What children learn from us may be different from what we want or expect. To illustrate this, I would like to paraphrase from an astute observer of children, Bill Cosby. He shows us that children can learn three things about us parents: we cannot see, we cannot hear, and we cannot remember. You hear a noise in your child's room. You open the door and he is bouncing up and down on the bed. You watch this for a minute or so and finally say: "What are you doing?" He figures that if you can't see, he's not going to tell you. So he says: "Nothing." And here many of us say something which must give the child further proof of our inability to understand reality. We say: "Well, you better stop doing nothing right now!"

Children also learn we do not listen very well. Riding in a car, a little boy says: "Can we stop and get an ice cream cone?" Mother says: "No, we are going straight home." A few minutes later he says: "Oh, look, there's a Dairy Queen." And the father says: "What did your mother just say?" So children learn that adults do not listen to each other. They also learn that we cannot remember. Ask any child and he will tell you that parents have very short attention spans. You get your child dressed up

to go out and tell him not to go outside because it has been raining. A minute later you look out the window and see him playing outside. You go out in anger--and here is where he learns you have a short memory--you look him straight in the eye, and say: "What did I just tell you two minutes ago?" He is no dummy. He figures if you cannot remember, he is not going to tell you!

I wanted to present a platform of irrefutable do's and don't's for disciplining a child with cancer. I could, for instance, insist that parents be very careful not to indulge or overprotect their child, but parents are well aware that neither of these is good. I could remind you that to act as if your child is going to die, when in fact he may not, might deprive him or her of some important aspects of living. But all of you know that and want to give your child as much life as possible. I could, for instance, remind you that to discipline your child in a hard and determined fashion might create guilt and regret later, whether your child lives or dies. But you knew that before your child became sick. I could, for instance, lay out specific rules gathered from various books on discipline techniques and tell you how to train your child to act exactly as you want him to act. But you already know that accurate and consistent use of rewards and punishments will do that, even if that is a desirable goal for you. I could, for instance, exhort you to act toward your child as if he or she did not have cancer, to act as if nothing really has happened, as if your child is in no way different. But you know that isn't quite true.

We must start with the basics. What to do is the question. But I have yet to be convinced--and I might as well say this at the beginning--that this question is truly basically different for the parents of a child with cancer than for other parents. This does not mean that the child with cancer should not have special considerations. It means that discipline is not radically different in quantity or quality because a child has cancer. If you begin with the premise that discipline must be basically different, then you must assume the child is basically different and you want to keep him basically different from his peers, and eventually from other adults.

What Is Discipline? What Is a Discipline Problem?

We should take a serious look at what discipline means. I would define discipline very broadly, simply as a reaction of an adult to something a child does or does not do. The root of discipline

is always in the adult's evaluation of and reaction to the child. This idea is very important, because we often think of discipline as a set of rules or procedures for correcting behavior, without recognizing that whatever action the adult takes is based on the adult's evaluation of what the child did or did not do.

The heart of discipline lies in the adult's emotion and behavior, not in the child. I will get to that later. However, I think it is safe to say that when we commonly think of discipline, we think of a reaction of an adult when a child does something we do not want or like, that we think inappropriate, unsociable, unethical, not appropriate for that age, or not to his benefit.

I must underscore that we discipline and correct when a child does something that is disturbing to us; 99 times out of 100 it is not disturbing to the child. The child tells a lie. He is not disturbed by telling the lie. In fact, he may have told the lie precisely out of a motive not to be disturbed. A child is not disturbed by picking his nose in public, or staying up past his bedtime, or not eating when he feels no appetite. We are. We should be fully aware that it is our values which are in some way disturbed that motivate us to correct the child or make a punishment.

It is unfortunate that the word "discipline" has negative connotations. We often think of correcting a child only when he does wrong. I call this the "rocketship concept" of discipline. If a rocket is on course, nothing is done. It is only when it veers off course that we take measures to correct its path. But if we accept discipline as a part of growing up and an integral part of the relationship between a child and a parent, it won't seem so unnatural or out of the ordinary, and we will admit that we are disciplining our children any time they learn something from us. We know they learn a lot more from us than they do in those brief discipline encounters.

Why do we think it is discipline when we punish a child for lying, and do not think it is discipline when we teach our children the value of telling the truth by being truthful with ourselves and with them? Discipline has never been, is not, and never will be simply a matter of learning techniques to control the child to our expectations. If that is what we think, there is a lot we have to learn about how children grow up and learn.

Discipline Problems with Children Who Have Cancer

Prior to this conference, a questionnaire was handed out about discipline. I will comment on only one aspect of this questionnaire. It was noted that about two-thirds of the parents saw a lack of knowledge about what to expect from treatment and disease as a major handicap in disciplining the child. The focus of discipline seemed to be on how to get the child to do something such as accept medicine, cope with procedures, eat, and so forth. I have to ask: Is the need to discipline a child with cancer so different that parents need to know exactly what to expect in order to prepare specific methods for correcting the child's negative reaction to disease and treatment?

It seems to me the problem of lack of information does not need to be answered by bigger, better, or specific discipline techniques per se, but by better communication between parents and medical personnel, parents and parents, and most importantly, by involving a child more and more in his disease and treatment. The more you involve a child in taking personal responsibility for his involvement with his disease and treatment, the less he will need to misbehave and to express his frustrations in unacceptable ways. I think Dr. Wilbur's comments this morning in his presentation were apt on this point.

I would like to see a questionnaire for children asking them what they see. I am going to give you a list of some things I have asked children about the problems they have with their parents. These are some of the things that they have said:

(1) "Every time the doctor asks me how I feel, my mother always answers for me. How come they never let me talk?" (2) "My parents said they would do whatever is necessary to cure this disease but they said they can't pay the bills, so I think maybe I shouldn't go to the hospital." (3) "My mother told me to go to school, but to stay away from kids who have colds, so maybe I shouldn't go to school at all." (4) "My mother tells me that bone marrow doesn't hurt, but I know it does, so why does she tell me that?" (5) "If I don't want to go to school, I just tell them, and they always let me stay home." (6) "I never let my parents know how I really feel, because I know it upsets them." (7) "The doctor said I could play football, but my mother said she didn't want me to because she thought I would get hurt." (8) "They always say I can have whatever I want, but they never ask me what kind of medicines I want or how to take them or when I want to take them."

The last one is especially poignant for me because we held a

conference recently at M. D. Anderson, and a teenager told me this afterwards: "My mother didn't want me to go to the seminar on cancer because she thought they might say something that would hurt me, but I am the one who has cancer."

Reinterpretation of the Discipline Problem

So what are some answers in disciplining a child who has cancer? To answer this we must remember that the basic issue in child-rearing is not discipline, but the relationship between the child and the adult. Furthermore, discipline is never an unemotional act. It is laden with feelings on the part of both the child and the parent. We have to recognize this fully in order to appreciate what it truly means to discipline a child, not only in getting him to behave differently, but above all, in helping him grow and understand his own particular situation and emotions.

Parents, whether their child has cancer or not, will have discipline problems precisely in those areas of life in which they themselves feel confused, are in disagreement, or are anxious, uncertain, or frustrated. The basic questions parents should ask themselves are: How do they feel about their child now? What expectations do they have, not what expectations do the doctors have? What do they want their child to learn about life and the disease? In other words, what are your goals for your child? If you say: "My goal is for him to eat, but I feel bad about forcing him to eat," then that needs work. If you say: "I don't know how to teach him how to accept his amputation," and follow it with: "We have never really accepted it ourselves," then that is what needs work.

I am fully aware that parents always ask for techniques and often become frustrated when an "expert" does not offer them the specific techniques. But I can only assure you that I have never seen a technique work until or unless the parent really examines his goals and motives for the child. And although the parents in the questionnaire said they knew why the problems arose and did not need more information, I disagree. Problems can be and are often initiated from disease and treatment. But they persist for psychological reasons. Problems do not arise because of a lack of information about disease, but from parents' reaction to that lack of information. Only with such a focus can a true psychological approach in understanding the problems be undertaken.

When someone comes in to see a physician, the doctor has a schema in his head as to what to look for in terms of symptoms or

problems. This schema is what I keep in my head when I see a discipline problem. Let me explain it briefly. (Figure 1).

FIGURE 1*

Parent's Behavior	Child's Feeling	Child's Goal	Parent's Feeling	Parent's Reaction
1. Pamper	Wants & expects attention and service	Attention	Annoyed	Reminds & Coaxes
2. Use power, authority; criticize	Wants to be boss; get some of the power	Show power; oppose, threat	Provoked	"You can't get away with this." Joins power struggle.
3. Disrespect, unfair	Hurt	Revenge; get even	Hurt	"I'll get even back!"
4. Don't encourage; favor sibling	Wants to be left alone; discouraged	Displays inadequacy	Despair; helpless	"I don't know what to do."

* This Figure is adapted from several works of Rudolf Dreikurs, particularly the following: R. Dreikurs, Coping With Children's Misbehavior. New York: Hawthorne Books, Inc., 1972 (1948); R. Dreikurs and P. Cassel, Discipline Without Tears. New York: Hawthorne Books, Inc., 1972.

This schema shows four types of misbehaviors according to the child's goal. It is based on a sound psychological principle: the child's behavior is a function of what he experiences in his environment. Reading across, if the child is pampered or experiences over-indulgence (first row), he will come to learn to expect attention and service. To get attention and have others do for him will become his goal. When he does this, others will become annoyed and will remind, coax, and do for him. In other words, adults end up working exactly toward the child's goal and thus the problem, is perpetuated.

The same thing occurs with the other three rows. If a child experiences adults using power and authority, he will show his own power, oppose, or threaten. Adults become provoked and utilize even more power and authority in an effort not to lose the battle. This is the power struggle which occurs so often. If, as in the third row, the child experiences disrespect, he will feel hurt and want to strike back. Adults, especially parents, are hurt in return, and as much as we hate to admit it, we often try to get back. If we don't exactly try to get back, at least we will become angry, and the child will interpret this anger as some kind of revenge. If the child experiences a lack of true encouragement (row four), he will become discouraged. He will then behave in a manner that shows us that he is inadequate and discouraged; we start feeling helpless, and throw up our hands.

The key to this schema is in the fourth column: the parent's feeling. Examining how you truly feel when the child misbehaves will show you what the problem really is. Once you know that, you can change your behavior in the first and last columns. What technique you choose is really not of major concern as long as you are consistent and understand the child's goal.

At first, one might think that this schema does not have much to do with problems in cancer, but I do not see one problem I have heard mentioned, that does not relate to one of these areas. Further, this approach of understanding the current emotions of the child and of the parent actually sets aside the often unanswerable question as to how the problem truly arose in the first place and focuses on what is going on now.

First, if you find yourself annoyed or somewhat frustrated with your child and find yourself reminding or coaxing him, chances are that you have over-indulged or done too much for your child. Any time a parent tells me, usually in a laughing manner, "My child is really spoiled," I always say, "Tell me exactly what you have done to spoil him." After the parent mentions a rather

long list of ways that he or she has spoiled the child, it becomes a simple matter of putting a stop to those things, because they are never things essential to the child's welfare. Quite frequently the anxiety of parents to change here is: "But then I will feel like a bad parent because I am not giving my child what he needs." At this point, the parent needs to understand that being a good parent has nothing to do with the unessential physical things you give a child. Ultimately, the child knows this also. Being a spoiled or pampered child who receives negative reactions from adults is not a very comfortable position for a child to be in.

Secondly, if you feel provoked, notice if you have been using your power or your authority in getting the child to cooperate with treatment. The only way to get out of a power struggle is simply to get out of it. One may have to change the tactic. Instead of using power or authority in getting the child to cooperate, you might spend more time in helping the child understand his disease, so that he takes responsibility and realizes that he has some control over the situation. But parents fear that the child will get total control, and possibly stop treatment. But I really believe that this fear is unwarranted. Children want to know what adults' rules are. Once they understand the rules of the game, they play very well.

Thirdly, if you feel hurt or angry, then you may have to look and see where you perhaps have been feeling negative toward your child because he has cancer. In this third row it is very important for parents, especially spouses to together examine their true feelings toward the child and toward the disease.

Fourthly, if a child is appearing discouraged, it is very important to find out why. It may be the disease or the treatments, it may be peer relationships, it may be your reaction to his disease, or it may be the family's feelings of helplessness that he is reacting to. It is very important to understand that in this situation, the child is showing that he is helpless because he really doesn't feel he can do any better.

Conclusion

Every parent who has a child with cancer wants that child to be normal. First and foremost, parents want their child to be physically normal, i.e., free of the disease. For it is the disease that most threatens the child's and family's life. The disease is a reality, to the child as much as to the parents and

medical personnel. To act as if the child did not have cancer will create an abnormal situation for the child, just as much as if one were to act as though the cancer was all that existed.

In order to look at the continuous problem of what is normal or what is the right discipline, we need to develop two ideas. First, let us not forget our own humanity and our own childhoods. All of us had imperfect childhoods in many ways. All of us misbehaved, and all of us--like one of the teenagers said on the panel--did many things our parents never knew about. We should not equate normal with perfect. In fact, when parents attempt to create a perfect child, emotional and behavioral problems most usually result.

The second idea is that we should begin to acknowledge that it is normal for the child with cancer to have cancer and have treatment.** What is normal for the child who has cancer is to have cancer and be a child at the same time. Hence, it can be considered normal if the child does not like getting shots, or shows negative reactions to loss of hair or resents intrusions into his routine. These reactions occur, not because he has cancer, but because he is a child. Likewise, he will need to be allowed to deviate at times from our ideal expectations of him, not because he is a child, but because he has cancer. Only when we adults truly examine ourselves to understand our feelings about his being both a child and having cancer, will he be able to accept and be comfortable with himself and the cancer. When that is done, discipline will take a more natural place in rearing the child with cancer.

** This was the topic of a workshop held by the University of Texas System Cancer Center, M. D. Anderson Hospital and Tumor Institute, Department of Pediatrics. See: The Normally Sick Child. J. van Eys, ed. University Park Press. Baltimore, 1979.

QUESTIONS AND ANSWERS

[Q]: Dr. Lucas, how do you deal with overprotectiveness on the part of others--grandparents or neighbors?

[DR. LUCAS]: There are really two issues here. First, I have to assume that parents who raise this as a problem are perceiving overprotectiveness on the part of others and are displeased with it. Remember what I said in my talk: a problem arises when we are disturbed in some way. So I assume I am dealing with parents

who (a) think that the overprotection from others is not helping their child, and (b) are not collaborating with or encouraging the overprotection.

Secondly, I would emphasize to these parents that they are in charge of their child. Cancer does not lessen the duties and responsibilities of parents. As I said earlier, discipline for the child with cancer should not be different in quantity or quality than for other children. Therefore, parents may have to uphold this view quite strongly when others want to change radically their relationship with the child in directions that may be harmful, such as overprotection or overindulgence.

I hear more complaints in this area about grandparents than about other segments of the extended family or community. When a child becomes seriously ill, the mother may rely on her own mother for help. This often creates a situation in which the grandmother perceives a need for more involvement in the child's upbringing. Illness of a child often draws grandparents into a more active and vocal role. If the parents have had past difficulty saying "no" to the grandparents, then during a time of crisis the parents may be even less inclined to take a firm stance. Often, an examination of the parent's relationships with their own parents in light of their goals for their child will be helpful.

Finally, ignorance about childhood cancer may be a major cause of overprotectiveness on the part of relatives, friends, and the community at large. If the parents present themselves as helpless in the face of this disease, it will allow and actively encourage others to "step in," to do something for the child.

The best prevention for overprotectiveness is for parents, as early as possible, to take the lead in explaining the disease and their continued plans for how they want to raise their child to others. For example, conferences with school authorities and the teacher may well head off special and unwarranted treatment when the child returns to the classroom.

[Q]: Do we then assume that if one truly enjoys spending time with his child, the parent is doing a good job of guiding the child's life?

[DR. LUCAS]: Yes. In my presentation I tried to focus on problems that might arise and how to view them. I did not mean to imply that the four problem areas are rampant among the parents and children who have cancer. Enjoying time with your child is probably the best touchstone of a good relationship. Parents who feel that they can no longer enjoy their child after

he is diagnosed with cancer become discouraged parents. And a discouraged parent may be the most difficult discipline problem there is. So we must learn to encourage each other, not in a false or hollow way, but in a way that truly engenders courage of convictions. We should remember that a crisis presents its unwilling participants with both danger and opportunity. From what I have seen previously, and from what I have heard the past few days, it is quite obvious that the crisis of cancer can provide parents and children with as many, if not more, opportunities for close relationships as before, despite a unanimous wish that it would never have happened and could be treated with complete cure.

[Q]: Do you work in a hospital, or do you have contact with families, and do you think it is important to have a psychologist working with the hematology clinic? If so, how do you get one in the clinic?

[DR. LUCAS]: I am on the staff of M. D. Anderson Hospital as a staff psychologist, and I am an Assistant Professor of Pediatrics. I spend all of my time at Anderson, which is a cancer hospital, so all of my patients have cancer. The question was, "Do you work at a hospital or do you have contact with families?" The answer is "Yes, I have contact with families, when they are at the hospital." Only one out of ten of our patients come from the Houston area, so I am very limited in terms of getting out to the families' homes.

Consequently, I really don't see any siblings unless they happen to come to the hospital. And because people come to us from such long distances, they don't bring along brothers and sisters. It is extremely difficult.

The other question was: "Do you think it is important to have a psychologist working with the hematology clinic?" Yes. I am not going to undercut myself. If you stop to think that about one out of every ten children may need some sort of professional psychological help, just by being a cross-section of the population, if you consider that the crisis of having cancer can create in the child or one family member, a crisis that may need some short-term help at minimum, you multiply the number of possible needs for help in families tremendously. If you see 1,000 patients, that means 100 to 200 patients will be in need of some kind of help just by being human beings, not because they have cancer.

So, yes, the question is, how do you get one in the clinic? There are two routes you can take. One, you have someone--in our

case, the head of our department, Jan van Eys, at M. D. Anderson Hospital, say, "I want one." If you have a powerful man in the institution, a physician who is head of the department of pediatrics, he may be able to get one. Or, you shell out a lot of cash and ask for a consultant to come in. I am biased. I think the psychologist should spend all day there. The person who comes in 1 or 2 hours a week doesn't know what it is like. It is difficult enough that I don't know what it is like because I don't have a child with cancer, and don't live with it 24 hours a day. But I am at least present, at least 10 hours a day, with enough families, that hopefully it gives me a little feel. A person who comes from the outside may not have the feel day in and day out.

I don't know how else you get a psychologist in the hospital. There is a tremendous interest among psychologists in the area of cancer, as you all know. You need someone powerful in your hospital who wants someone badly enough.

2. Cancer and Nutrition

Robert I. Henkin, M.D.

As you may know, there has been a great interest in nutrition and cancer in recent weeks. In fact, last week, at the hearings in the United States Senate, there was a great deal of activity and interest in just this topic, and the topic is vast, and we know very little about the problems.

What I want to do today, is to share some of our awareness of the problem with you, and to tell you what we know, and perhaps a little about what we do not know. As it came out in the Senate session, Senator McGovern felt that at least half of the cancers caused in the United States were due to dietary factors. That number is perhaps a bit exaggerated, but I think the first thing I want to talk about is the relationship of diet as an etiological factor in the induction of cancer.

We know very little about this, and perhaps the best data that are available relate to religious groups, such as the Seventh Day Adventists or the Mormons, who show a 30 percent lower incidence of cancer compared with other groups. The reason could be their dietary preferences, or at least, we think, related to dietary factors which may be key in this issue.

This is one of the major factors that tends to make us think that diet and nutrition in cancer are related.

There are other factors we find even more pervasive in this whole issue: longevity and survival in relationship to nutrition and cancer. It appears that weight loss in cancer is very important

in terms of survival; the greater the weight loss, the shorter the survival time. Anorexia, the loss of appetite and intake of food, is clearly related in some way which we don't yet understand, to the survival of patients with cancer.

However, you just heard Dr. Lucas talk about the issue of eating and forcing people to eat, and realize that this is indeed a difficult area.

Last, I want to talk about the strategies that one might use to try in treating these kinds of problems: (1) the etiological factors; (2) survival; and (3) treatment. I thought I would present some data to you so you could get an idea of what we know and what we don't know, and then during the question section we could perhaps interact more fully.

First, an adult who has manifestations of what we call anorexia is significantly depleted of both protein, carbohydrates, and fat, a typical type of pattern. We do not see this as often in children, as in older adults. The important thing to realize is that this is not related to all cancers, but only to particular ones. I will talk about that later.

In the United States during the period beginning with the year 1900 and ending in 1975, we have seen a tremendous increase in heart disease and also in cancer. We have found decreases in diseases such as tuberculosis and influenza based upon our utilization of antibiotics.

Perhaps among the factors that relate to the increased incidence of cancer are: the increased use of tobacco, X-rays, exposures to carcinogens, and the environment. I guess this is where the Senate got its information that diet might be the major factor. It certainly is one among many.

Scientists at various places have taken a look at dietary intake and changes, in relationship to the increased incidence of cancer. From 1860 to 1980 in the United States population, there has been a tremendous increase in the use of refined sugar.

There has also been an increase in the consumption of meat, poultry, and fish in the United States. The decrease in 1942-46 was related to the lack of such foods during the Second World War.

Over the same period of time, there was a decrease in the intake of dietary fiber. There has been an increase in caloric density or the total amount of calories one is taking in. People who are concerned about diet and cancer point to factors such as increase

in sugar intake, increase in fat and protein intake, a decrease in the intake of fiber, and the increase in calories as possibly involved in cancer etiology.

Now, whether or not these factors are indeed related to the increased incidence of cancer, is not proven in any way. We could also consider the increased number of television sets that have been made in the United States, or the number of telephones that are in homes, and they also would increase over this period of time.

So, there are a number of factors which may or may not be related to the increased incidence of cancer. Certainly, cancer is a disease of the aged, not necessarily of children. Thus, when we talk about the incidence and etiology of nutrition and diet in cancer, even though these factors seem important in some ways, I am somewhat cautious about overinterpreting the data.

We will look at some of our data in relationship to the weight loss that we have seen in patients with cancer at the time of presentation. We have been looking at the relationship of weight change in patients with different kinds of tumors and with diseases of various types over the years. We can see that in some diseases there are significant changes in weight at the time the disease occurs.

In cancer of the oral cavity, for example, there are obviously significant weight loss characteristics. The same phenomena occur with cancers of the gastrointestinal tract, the stomach, the colon, the pancreas, and organs such as the liver. In lung tumors, one sees a significant weight loss, whereas with breast cancers there is, if anything a weight gain or no change at all, so that the anorexia and the weight changes that we see, may play some role in helping us understand something about the characteristics of the treatment, and perhaps some aspects of diagnosis.

A number of institutions are involved in an anorexia cancer study supported by the National Cancer Institute, from Northwestern University and the University of Buffalo, as well as our own group, and we see the same kinds of phenomena. When we look at mean weight change, we see that with breast tumors there is very little weight loss. The greatest change in weight occurs with tumors of the lung. We are very impressed with that. The mean weight decrease over normal, usual, weight in patients with lung tumors is about 30 pounds. With these significant weight changes in patients with tumors of the lung we are concerned with the reasons that cause this problem.

The other large category of weight loss is with cancer of the ovary, and again we are not sure of the relationship between anorexia, weight loss, and the tumor.

Data obtained by Dr. Shils, at Memorial Hospital in New York City, shows the same phenomenon. There is significant weight loss associated with diseases of the GI tract and he uses the words dysphagia and anorexia, anorexia meaning weight loss, dysphagia meaning problems with swallowing. Here we begin to see that there may be sensory factors that relate to these changes.

There certainly is some relationship between anorexia and weight loss and specific tumor types. Survival among patients with tumors, particularly lung tumors, has been greatest for those who have lost the least amount of weight, or those whose weight has been most stable, regardless of treatment. The results are the same in spite of radiation, surgery, chemotherapy, or combinations. Other tumors in which weight loss and survival seem particularly reflected are those involving the gastrointestinal tract, ovary, liver and pancreas, and head and neck. This whole issue of malnutrition and cancer was recognized many years ago. As many as one-third of patients with cancer were dying of malnutrition in the 1930's, as well as today.

Of course, the question we ask ourselves is, how is it so many patients die of malnutrition with the disease? And, of course, this is a very difficult problem, and one with which we have not yet come to grips.

Changes in oral sensation related to the disease process may also influence nutrition. Data from patients who were treated with radiation to the oral cavity and to other sites in the head and neck area as well, show that these patients complain of taste loss, anorexia, weight loss, and dysgeusia. Dysguesia means that food tastes peculiar, odd, bad, or rotten to the patients. Of the 18 patients in the study, 16 were aware of some degree of taste loss, 17 were aware of a decrease in appetite, and 12 were aware of the fact that food tasted awful. When we measured their taste thresholds, we indeed found there was an abnormality in the ability to taste in each patient.

In a larger group of patients that we have seen at the Georgetown University Hospital at our center, there is very little taste loss or distortion among patients with breast cancer, but among patients with cancer of the head and neck, lung, or ovary, there are changes in their ability to taste. So this may be related to specific tumors, and may be of importance in terms of helping us understand some aspect of these diseases.

In another area of concern are factors that influence nutrition in patients with cancer. The trace metals, zinc, and copper -- particularly, zinc, seem to be important. If we look at these cancer patients, the mean serum level of zinc is 74 micrograms per 100 ml. of blood; this level is significantly lower than in normal subjects or in patients without cancer. Conversely in patients with cancer, the mean serum copper levels are elevated.

Recently, we have studied saliva zinc. We see that salivary zinc levels are also lower than normal in patients with cancer, and in relation to a series of studies recently carried out, we are now beginning to realize that zinc plays a very significant role in appetite, taste, and other factors that influence the intake of food. We begin to have some clues for the first time that might relate to understanding something about the anorexia and sensory factors that are seen in cancer patients.

We begin to think that perhaps zinc, which is so important in the synthesis of protein, might be one factor that could influence the anorexia and the sensory changes which we see in patients with cancer.

In a small study that we did at the National Institutes of Health some years ago, we took a small number of patients who had changes in taste following radiation and looked at their serum and urine zinc levels. We found, again, the same thing we saw in the patients of the more recent study, that blood levels of zinc were low, and that the patients had abnormalities of taste. What we did, then, was to treat these patients with zinc.

With treatment, we were then able to return taste thresholds to normal or toward normal, and we were able to increase the patients' appetites and, of course, their serum zinc levels, which were normalized on treatment. This seems like a very interesting study, but the problem is that it was uncontrolled and is, primarily, provocative, other than definitive. There are some more recent studies which we think may be more important.

We have been looking at patients with lung tumors, and looking at their response not only to zinc as a mode of therapy but, also, to zinc plus chemotherapy. These studies are still very preliminary. However, with the utilization of zinc as a way of maintaining appetite and maintaining body zinc levels, along with the use of chemotherapy, we seem to see not only a regression of the tumor but the maintenance of appetite, the ability to withstand the rigors of chemotherapy better, and a further increase in survival than we had seen previously.

Now, the number of patients we have studied is few and, again, we have not yet run any controlled clinical trials, but we have been impressed with these early data, particularly because the types of lung tumors we have been treating have been kinds that are commonly resistant to therapy. We raise the question of whether zinc, which is so important to protein synthesis and the making of new tissue, might not only produce an increase in appetite, but also in tumor turnover. Hence, when chemotherapy is also utilized, we take advantage of the zinc more fully, both in terms of the treatment of the tumor, as well as increasing intake of food.

Obviously, that is a speculation, a hypothesis that remains to be tested. But we think that this whole issue may be very important, and the relationship of diet and cancer and nutrition may be related, not simply to etiology, but, also, to treatments as well.

Since we feel--and data bear us out--that longevity after the cancer is discovered relates in part to weight loss, there are surgical techniques that can be used to increase the intake of foods: installation of food through a gastrostomy (a surgical placement of a feeding tube directly into the stomach), or through utilization of parenteral hyperalimentation. Hyperalimentation is extremely expensive and difficult. However, it is certainly important to some patients, but there should be some other way, we think, of increasing food intake.

Behavior modification is certainly one technique, and other techniques using psychological factors could be used, but, so far, that has not been very effective. Diet modification is one strategy that has been used. The problem is that food companies have not been too helpful in terms of optimizing the test type of food or meal interest to increase dietary intake.

We have also thought about hormonal changes that might be used, but these have not been terribly helpful. We just talked about some mineral changes that might play a role.

The point is, we know very little about how to increase food intake. We are searching for techniques to use. The purpose of our studies at our Center initially, was to find out what questions we might ask so that we might be able to develop answers, and perhaps we would be able to come to grips with some of the issues.

So, what we are left with is basically what I mentioned in the beginning in relationship to nutrition and cancer. One, etiology

of cancer may have some functional relationship to diet. We are not very clear about this relationship. Two, from our data and from that of others, I think there is no question now that weight loss and survival are related. The incidence of anorexia is a very dire sign in terms of survival of patients with cancer, be they youngsters or older patients.

The third thing, which is perhaps the most important to us, relates to the whole issue of treatment. We know very little about this, and we need more patients, like yourselves, to allow us an opportunity to understand and investigate these issues. Only with an awareness and understanding of the relationship between nutrition and cancer treatment, will we get at one of the key factors we think is important in the survival of patients with cancer.

QUESTIONS AND ANSWERS

[Q]: Dr. Henkin, do you have any information on the high risk of vitamin A suppositories?

[DR. HENKIN]: In animal studies, vitamin A has been evaluated and appears to have some role as an anti-carcinogenic agent. The exact role is not completely clear, so its application is not clear at the present time. Vitamin A has a role to play in oncology and in tissues of the body, and therefore could be of value, but its efficacy has never been clinically investigated in any serious way. But it is a very interesting and important area.

[Q]: Since infection stimulates the immune system, do you think the increase in cancer may be due to a decrease in infection?

[DR. HENKIN]: The relationship of the immune system to cancer is one that is complex and unclear at the present time. For example, one of the philosophies now used in the treatment of cancer is that of trying to stimulate the immune system to respond in a more appropriate way, since anergy seems to be so prevalent among patients with certain kinds of cancer. We now find that zinc is the only physiological mitogen which will make lymphocytes divide in vitro. So there may be nutritional factors which could be important in this whole relationship. Other investigators feel the changes in the immune system might not be the cause, but might be related to the end results of the cancer. So it is a very complex story, and the role of infection in this whole issue is obviously complicated by the roles that therapy and the drugs

that are used to treat cancer play, since they might themselves produce injury to the immune system of the body and to its ability to fight infection.

[Q]: What is the importance of selenium in the soil? Are these findings true, and how can we as parents supplement zinc in the diet?

[DR. HENKIN]: There are fascinating studies that were carried out by biochemists at the University of San Diego. As part of an epidemiological survey they have shown, that among patients or among nations in which the selenium levels are low, there is the highest incidence of cancer. Some data in animals suggest that eating selenium may be protective against cancer. Now, in a country like New Zealand, which has the lowest level of selenium in the soil of any country in the world, one finds the highest incidence of cancer. However, there are other risk factors in New Zealand that are also prevalent in other advanced countries, high sugar and fat consumption, and decreased fiber consumption.

Selenium may be an important factor, and is one substance that interests many of us in nutrition and cancer. Again, I am afraid I will have to say that we have very little information. No one has ever studied selenium levels in cancer patients, or tried to intervene in a systematic way with selenium in the treatment or prevention of cancer. The few studies that exist were carried out in animals and are at best, suggestive.

[Q]: How can we as parents supplement zinc in the diet?

[DR. HENKIN]: Zinc promotes the protein synthesis in all tissues, being involved as a cofactor in the enzyme DNA polymerase. In malnutrition, the model usually promulgated is that the tumor will rob whatever it can, i.e., zinc, from the rest of the body. These results have been interpreted by some investigators to mean that it may not be wise to provide more nutrients or take in more food. This formulation may not be entirely appropriate. It may be important to put together more accurate nutrition knowledge, including effects of adequate chemotherapy treatment programs on tumor growth. I think one has to look carefully at this whole problem of nutrition in cancer in relation to treatment. It is simply not enough to take zinc as a treatment of malnutrition.

The specific answer to the question is that there are foods rich in zinc. These include shellfish of all kinds, red meat, white meat of fowl, organ foods such as sweetbreads and liver, and nuts. Zinc is also available as a dietary supplement even in drugstores. But remember that both micronutrients and macro-

nutrients are extremely important in a balanced approach to the whole patient. Looking at one aspect separately is not going to be helpful, and could be harmful.

[Q]: What role does vitamin therapy play in children with cancer?

[DR. HENKIN]: Obviously, in any patient who is malnourished, vitamins are important. But we really don't know what specific role vitamins play. We really don't know, and of course one might assume that there are multiple abnormalities that are involved with vitamin as well as with mineral deficiencies in cancer. I think that we need to know more, and research really is not as active as it should be to answer that question.

[Q]: Does the survival rate include those patients with initial weight loss who later regained their weight?

[DR. HENKIN]: The results I have discussed are basically those dealing with mean values, i.e., the average of the 575 patients studied over a period of 3 years. Conditions varied from patient to patient. I think the data show very closely that regardless of whether the weight loss occurred early or late, a significant loss, as indicated by a loss of 5 percent of body weight or greater, when that occurred, was associated with shortened survival. The specific effects of weight gain, either with adequate nutrition or with proper therapy in remission, are not known yet, although historically it appears that the more normal the weight the longer the survival. We have not yet addressed ourselves to the specific question you asked, which does deserve study.

[Q]: Is there a relationship between zinc-copper levels and connection with relapse in cancer patients?

[DR. HENKIN]: Some investigators think so, particularly in terms of diseases like lymphoma and Hodgkin's disease. We are not sure what the levels in blood specifically mean. We know that copper is a so-called phase reactant. When one gets ill for any reason serum copper levels go up and the zinc levels go down. These changes may be nonspecific and not very important for our purposes here. In remission, the levels become more normal. That is, the zinc goes up, returning to more normal levels and the copper levels in the blood go down also returning to more normal levels. When there is a relapse, the values appear to diverge again. As Dr. Forman discussed, when his patients with leukemia would relapse, he would almost uniformly see, as we do, this divergence in copper and zinc levels in the blood.

[Q]: Is it possible that taste changes in cancer patients may be due merely to the biochemical changes associated with depression?

[DR. HENKIN]: That is a very good question. Unfortunately, we know very little about the taste changes which occur in depression, and therefore I can't answer in detail. We have studied a few patients who were depressed in relation to psychological or psychiatric illness, and by and large, they don't have taste dysfunctions as a major factor in their disease. Again, we do not have systematic studies. There is no question that when you get depressed, appetite decreases. You don't eat so much, but whether or not there are biochemical changes which go along with that, I don't think is known.

[Q]: Can the change in taste be directly related to the type of cancer or medications?

[DR. HENKIN]: Yes, and that question raises the issue that the changes that we see in sensory phenomena, in taste or smell, can occur not only from the disease itself but also from the treatment of the cancer. Sometimes the chemotherapy or radiation treatment, as Dr. Mossman, who works with me, has shown, can produce some of these changes. What these interrelationships are, again, are not entirely clear or specific. Chemotherapeutic agents which interfere with protein synthesis may readily affect taste and smell directly, since these systems are composed of tissues that turn over rapidly. We know that we can minimize some of these changes by appropriate strategies, but unfortunately, we have not applied these strategies as often as we might.

[Q]: Has zinc treatment been used to encourage a child's appetite, or are the studies limited to adults?

[DR. HENKIN]: Unfortunately, there are very few studies in which nutritional support has been given to either adult or pediatric patients to encourage an increase in appetites. So we can talk about it only anecdotally. We have given zinc to some children, and some of them do well, but again there are no definitive data. Other investigators have noted loss of appetite and taste dysfunction in zinc-deficient children and administration of zinc has been useful in correcting both their appetite loss and taste changes.

It is possible that we may be able to find other substances that may prove more effective in improving appetite in the future. In general, the myopia of us all in terms of looking at treatment only in relation to chemotherapy or other factors that relate to

standard therapy has not been extended to consider nutritional factors or factors that might influence food intake, as related to clinical remission.

[Q]: Our experience has been that our doctors do not consider nutrition as a major factor in treatment. Do you think this failing is common with doctors on a national basis?

[DR. HENKIN]: I would say unfortunately that it is true. Again, the physician feels that he must do something that is effective, and his training has been that drugs, radiation, or other chemical types of treatment are the way to go. And very little has been brought home in any practical way about nutrition. However, several investigators at Boston City Hospital and Boston Children's Hospital, have been using various nutritional modes of therapy and other nutritional factors along with the chemotherapy, and have found much better results in the short run in terms of patient survival and well-being.

[Q]: Are you familiar with and can you comment on Dr. Irving Stone's work with vitamin C as a preventative or cure for cancer?

[DR. HENKIN]: I have no information to answer that question at all.

[Q]: If a child has bad mouth sores, his eating habits deteriorate. He then loses weight. Isn't there some way the child's good nutrition can be maintained at home?

[DR. HENKIN]: There are local, as well as biochemically-related systemic factors that are involved in nutrition. We see this in patients who are irradiated. The problems they have with mouth sores, sore tongues, and oral ulcers, are significant problems. These local problems should be dealt with conservatively, for they influence acceptance of food. Local use of antibiotics and antiseptic and/or anesthetic mouth washes have some short-term value.

[Q]: Is the increase in the unsaturated fatty acids ratio a causative factor in cancer?

[DR. HENKIN]: Yes, the role of unsaturated fatty acids as a factor in prevention of cancer has been discussed and evaluated by a number of investigators. In animal studies, feeding diets that are high in unsaturated fats seem to be protective against cancer as opposed to diets that are rich in saturated fats. Again, this issue has not been well studied.

In terms of cardiac function, as in the Framingham study, eating diets high in polyunsaturated fatty acids has been useful in lowering blood cholesterol.

[Q]: How can you help prevent weight gain in a 4-year-old on Prednisone?

[DR. HENKIN]: The problem of water retention with Prednisone is a major one, and obviously that has to be worked out very carefully in relationship to the dosage of the steroid and the salt and water intake. Dietary care in relation to the limitation of salt intake can be useful in treatment of this problem. Remember that tap water may have significant amounts of sodium, so drinking distilled water may be of value.

[Q]: Are we better off eating only pure foods and no additives? Are there studies underway to prove or disprove this?

[DR. HENKIN]: There is interest but few studies are underway to investigate systematically the role of additives as major factors in the etiology of cancer in humans. There are data that additives such as saccharine, some substances found in food colorings, and nitrates have been associated with an increased incidence of tumors in experimental animals. So far studies dealing with these latter issues have been equivocal. There are also a number of parent groups that are concerned about additive factors and hyperactivity.

[Q]: How do we measure the effects of vitamins B, A, and E?

[DR. HENKIN]: The way that one measures adequacy of vitamin therapy is by function, and there are specific tests that will give information about functions of some B and A vitamins. Of course, you can measure levels in blood and tissues. Unfortunately, one can still get malfunction or inadequate function even though the vitamin levels in the blood, per se, might be what we call normal.

[Q]: Are there any studies you can refer us to on diets during chemotherapy?

[DR. HENKIN]: By that question, do you mean diets that might be advantageous in being synergistic with chemotherapy? Unfortunately, there are no published diets which relate to that. However, maintenance of adequate protein intake is important.

[Q]: If weight loss is related to survival, then maybe patients with more weight loss have more disease. Would you please

comment?

[DR. HENKIN]: I think the correlation is that patients who have a greater weight loss seem to have decreased survival. I don't know if the term "more disease" is the one that we want to use. Whether there is a bigger tumor or a greater tumor burden or a more malignant tumor, I don't think that is necessarily the case at all. The correlation we have been able to make, and it is all we can say at the present time, is that the greater the weight loss, the less the time of survival, and that so far is independent of disease.

[Q]: Why is there not one set diet given by doctors? Each has a whole different set of rules and do's and don't's.

[DR. HENKIN]: Again, when you get into an issue as emotional as cancer, I am sure you will find individual practitioners who might suggest one approach as opposed to another. And with the present state of knowledge, it is difficult to choose. Involved in this as you are, of course you will feel some need to go ahead and grasp at whatever might be nutritionally sound to help yourselves and your children. Unfortunately, we as professionals cannot provide you the kind of guidance that might be necessary. I wish we could. All I can say is that with more support, perhaps we may be able to do that.

[Q]: What do you do with a child who totally avoids whole groups of foods like vegetables and fruits, and eats sweets instead?

[DR. HENKIN]: That is a very difficult problem. Day to day preparation of food, in terms of what the family eats and what the child eats, and also in terms of what might be good and useful nutritionally, should be based on specific strategies used to influence food intake. One has to develop specific strategies for each child. It is impossible for me to generalize. With specific information it may be possible to come up with a specific strategy that might optimize a given child's diet and optimize caloric intake. There aren't any magic bullets and there is no single answer. What is important is that each person be treated individually with individual dietary likes, dislikes, and disease, evaluated separately. That is why it is as important for the physician to know about and deal with nutrition as to know about chemotherapy.

[Q]: My name is Dave Krecke. I am from Bethesda. Our son has a brain tumor, medulloblastoma, and he is recovering quite well now from surgery of a year ago. My son experienced a 10 percent weight loss shortly after the therapy began. It was difficult

for us as a family to look at him as having embarked upon a therapeutic treatment when he was wasting away before our very eyes.

My wife and I tried to get in touch with some of the nutrition people, and we found that much of the current nutritional investigation and research is not scientifically proven to be efficacious. There was suspicion on the part of our therapist regarding our going off to M. D. Anderson Hospital to have our son treated there.

[DR. HENKIN]: I can't help but sympathize with your feelings in all respects. In the last few years the whole issue of nutrition has been addressed more in the newspapers than in the halls of science. As you well know, the history of nutrition is a very great and glorious one, and the basis of biochemisty in the early 20's and 30's was formed by scientists who were interested in discovering the structure of vitamins and other related subjects.

Yet when the vitamins were characterized and their functions discovered, the issue of nutrition was pursued, not in the laboratories of biochemistry and medical schools, but in the classrooms of schools of home economics. The shift created the attitude that nutrition wasn't really very important or relevant to clinical medicine. Now we are back with nutrition as perhaps being very important clinically, but conservative, traditional establishment physicians still look upon this whole area as one of inadequate knowledge.

I wonder along with you, how it is possible for a physician to look at a patient wasting away and say, "Look, he is going to get better, don't worry, we are giving him the proper chemotherapy. He is going to end up being all right."

All I can say is that you are right. Physicians have to realize that they can't treat all cancers with drugs alone and that this issue of cancer and nutrition has to be dealt with in an integrated, realistic manner. Obviously, the physicians have the best interest of the patient at heart. They want to help your son, but they are myopic. They see what they want to see. They see that chemotherapy is going to do some good, and they don't consider the fact that the patient is losing weight. They may not even see it.

In fact, if you ask an oncologist whether the patient may lose weight, he might say, "very rarely," or "a little bit," when actually the patient is wasting away. So it means physicians have to be sensitized to the critical effects of nutrition in the

ultimate care of patients. Perhaps they should reread the articles written in the 30's in which malnutrition was found to be the cause of death in one-third of cancer patients. Of course, if you do that, you can antagonize them, because they feel you don't know anything about medicine. They are the physicians treating the patient. I wish there was something we could do to bring these issues to the attention of the oncologist, who then could act in an appropriate way to try to understand and deal with these issues. We in medicine have done this in the past with other problems and there is no reason why this won't involve us in the future. When more knowledge is available, 2, 5, or 10 years from now, we should be in a position to act to combine an appropriate nutritional approach with other programs.

[Q]: I am Barbara Jaeger from St. Louis. I have a degree in dietetics, and have also taken care of a little girl who was very sick with a cancer. I am going to speak on how to get a dietician. You as parents have the right to the services of a dietician in the health care center where your child is receiving treatment. After you request her services or go to the physician to request her services, and fail, then try to get to the hospital administration as a parents' group. As long as you yell and scream you may be able to get the services of a dietician. You might also want to go to your local dietetic associations where you may just find one or two dieticians who are very interested in working with patients who have cancer.

In St. Louis, we have a few. These dieticians really specialize in private health, which involves working with patients on an individual basis, trying to encourage them to eat. With their encouragement, patients do begin to eat and gain weight.

[Q]: I am Trudie Thompson, from Indiana. My daughter has lymphosarcoma. I want to encourage you to talk to your doctors about nutritional concerns. With just a little bit of prodding, doctors will respond. Generally, they are not trained in nutrition, but they now have hired dieticians just for the children with cancer and they are using more hyperalimentation. I want to ask, is there any benefit to it? They say the white count is higher with it, and there is weight gain.

[DR. HENKIN]: This discussion involves the use of parenteral hyperalimentation in treatment of patients with cancer. Initially it was used to minimize the eating problem of patients with gastrointestinal problems on a short-term basis. Then it was extended to other patients, such as patients given radiation who also had local oral problems. In general, it is extremely

effective as a short-term therapy, because whatever local or immediate problem was involved, the supply of calories allowed patients to maintain their weight.

One talks about usual caloric intake with normal intravenous therapy as between 500 and 800 calories a day. That is obviously not enough to maintain an adult. One has to develop strategies by which you can get thousands of calories usefully into a patient, to maintain weight. If we are talking about cancer, then the need to maintain 45 kilocalories per kilogram of body weight becomes a key factor, a key number to remember in terms of adequate nutritional support, and that can only be done by using some kind of technique that will allow those calories to go in. You either put them in through the stomach or you put them in intravenously.

The technique of parenteral hyperalimentation has been very useful, and has now been shown to be effective among some patients, and some study groups have been formed, (for example, the TPN study group in pediatric patients), to see if optimum nutritional support with TPN, in addition to proper or adequate chemotherapy or other forms of treatment, will provide better results. The initial results seem to be favorable.

Thus, this is an appropriate kind of therapy. The problem is that it is exceedingly expensive. You talk about $537 per month as the out-of-pocket expenses for a family. TPN costs at least $300 a day, and we are talking about therapy that is going to last for 6 months or 1 to 2 years. This is impossible financially so this will not be feasible in the long run.

And the method of nutritional support is entroalimentation, using newly developed lightweight tubes that can extend from the nose into the stomach for a period of weeks and months, without necessitating the problem of local tissue destruction. With this technique one can take a preblended diet and put it directly into the gastrointestinal tract. This doesn't cost as much money as parenteral hyperalimentation, but it can be equally effective.

Which patients use entroalimentation and which use parenteral hyperalimentation depends upon the patient's clinical condition, his underlying disease as his present or contemplated therapy. However, there are many physicians who have little idea of the use of TPN or entroalimentation.

We have little systematic understanding or awareness of the effectiveness of either TPN or entroalimentation as it applies to large groups of patients with diverse types of tumors. Thus, we

have a very difficult problem which cannot be generalized. The therapy must be specified for each individual patient, and the answer to your question is, yes, it is really important, but not necessarily imperative.

[Q]: I am from Dayton, Ohio, and I have a child who has leukemia. Obviously, this whole issue of nutrition and feeding the child is highly emotional at times, because one of our primary responsibilities is feeding the child, and you do get into more than furnishing nutrients for your child. I have engaged in many more power struggles with my children over eating than I would care to admit, and I am talking of any kids under any circumstances, whether ill or not. What foods do we eat? How often do we eat them? Do we clean our plate? Or do we leave food on the table? You end up involving yourself in a lot of disciplinary problems as well.

I had a child, not the one with leukemia, but another child who had a restricted diet for a very lengthy period, and I got to the point where my only thought was food. We started out in the morning and fixed breakfast. My next immediate thought was, what do we have for a snack, and then what do we get for dinner? I began to get a little paranoid. I wish I had some answers.

And I have a child right now who simply is not eating because of the drug she is on, and I am totally frustrated.

[Q]: Did one of the physicians explain the use of tetra-hydrocarbonal as an appetite stimulant?

[DR. HENKIN]: That question has been getting some response on the part of the government, because of the role of drugs such as marijuana in cancer patients. Marijuana seems to produce some effect on the stimulation of appetite. How that occurs is totally unknown, but this strategy could perhaps be useful in the treatment of cancer. The trouble is that one has some emotional hangups about this in terms of how to administer it, when, and to what groups of patients.

The studies that have been done on the relationship of increased appetite to the intake of marijuana have not been as carefully undertaken as a scientist might like, but there is enough smoke there to think that there could be something very useful.

3. The Cost of Cancer*

Jan Black

At the University of Kansas Medical Center, we have been investigating the stress the illness imposes upon various family members. And the financial burden of the illness has emerged as a major source of distress, second only to the disease itself. Of the financial concerns, nonmedical costs appear to be the most troublesome. Most patients have at least some third party coverage of medical expenses, and can usually arrange installment payments for the residual medical costs.

In contrast, the nonmedical expenses must be paid as they are incurred, and are rarely reimbursed. Despite the recent interest in the high cost of cancer care, little attention has been given to the nonmedical out-of-pocket expenditures. In view of the importance of this issue as reported by our patients, we conducted a pilot study in which six families of children in treatment for cancer reported their nonmedical expenses and loss of pay for 4 consecutive weeks. Half the people spent at least $453.74, including loss of pay and expenses. The result of this pilot study indicated far greater expenses than anticipated and prompted the current study.

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Parents of children in treatment for cancer by the pediatric hematology section of the University of Kansas Medical Center participated in the study. Families were recruited for the study during a clinic visit or hospital stay. To date, data from 70 families have been collected. This group represents approximately one-half the patients seen for active treatment and/or followup. Eighty-two percent of those asked have participated in the study. The study population included 70 family units ranging from three to seven persons with an average of 4.7. Of the 62 families with a father present, 60 fathers were employed and one was retired. Thirty-six of the mothers were gainfully employed outside the home. Half the families had an income of $13,000 or more. The parents ranged in age from 21 to 53 years, with median ages of 34.5 and 36.5 years, respectively, for mothers and fathers.

The patients consisted of 24 girls and 46 boys. Their average age at the time the data were collected was 9 years, ranging from less than 1 year to 18 years. Half the patients had been diagnosed at least 9 months. Diagnoses included leukemia, lymphoma, sarcomas, and a variety of other solid tumors. Approximately half of the families were located less than 55 miles from the hospital, but 12 families lived at least 165 miles away.

We asked our parents to complete two questionnaires weekly, a log of nonmedical expenditures and a log concerning parents' loss of pay. The nonmedical expenditures related to the child's illness were categorized into the same type of expenses as recorded in the pilot study:

(1) food, extra food brought to the patient, food eaten out, or fast and frozen food bought for the convenience of family members at home;

(2) lodging for parents while the child is hospitalized;

(3) transportation to and from the Medical Center, including parking and toll fees for the expressway;

(4) family care, care for siblings while the parents were at the Medical Center with the patient;

(5) clothing, the extra clothing bought because of the patient's weight gain or loss, or wigs; and

(6) miscellaneous expenses, including telephone calls to keep distant relatives informed of the child's condition, a room air conditioner bought to ease the

discomfort of the patient, or gifts for the patient and/or siblings left at home.

Parents also recorded the patient's hospital status, which was the level of care the patient required during the week for data collected. Categories were: (1) in-patient treatment, (hospitalization); (2) out-patient treatment; (3) no treatment; and (4) mixed, or change in status from in-patient to out-patient or vice versa.

The patient's performance status was obtained from parental interviews during each week of data collection. A performance scale score was assigned based upon the following modified version of Karofsky's scale of performance status. A score of "1" indicates that the child requires the equivalent of hospital care, is unable to care for himself. The score of 2 indicates that the child is unable to go to school, but able to live at home and care for most personal needs; 3 represents no limitation in activity, the child is able to carry out normal activities, no special care needed.

The second weekly log, which was completed separately by mothers and fathers, concerned the loss of pay. Items covered include usual paid working hours per day, hours of paid work missed, explanation of missed hours as sick leave, vacation, or other, numbers of hours and amounts of money paid to a substitute worker, actual money lost during the week of the illness, total family income. Mothers were also asked how much work they usually did unpaid, and we assumed at least 10 hours a day for home management.

The loss of pay log was added after collection of expense data was underway, and therefore we had only 32 families who reported loss of pay. Many of the measured expenses are directly tied to contacts with the hospital for evaluation or treatment. In order to avoid spuriously inflating cost figures by repeatedly sampling weeks when patients were seen at the Center, the following method was used to sample an average week.

One-third of the participants were asked to record expenses beginning 1 week after they were contacted. One-third were asked to begin in 2 weeks, and the remaining third were asked to begin on the day we contacted them. Each family was asked to record expenses for the period of 1 week every 3 months. We wanted to know what makes a difference in these expenses. We found out. We used a complicated statistical technique called multiple linear regression. This type of analysis allows one to ascertain the major factors included in cost, so that the total expenses

for a family can be estimated or predicted on the basis of a limited amount of information.

Variables to be predicted were the average family expenses in each category, transportation, food, lodging, clothing, family care, and miscellaneous, and the average total nonmedical expenditures. The factors we thought might influence cost were sex, age, parental occupation, income, family size, residence, as well as information about the patient's illness, level of care, performance status, time since diagnosis, and number of body sites of active disease.

Summary statistics were also computed from the data on the loss-of-pay questionnaire. The nonmedical, out-of-pocket expenses were then added to the loss of pay to yield a combined expense for those families completing both questionnaires. These combined expenses were expressed as a percentage of the weekly family income.

Half of our families had weekly expenses of $39.70 or more. The largest category of expenses was transportation, followed by food, and miscellaneous items. There were considerable variations in the expenses borne by these families as is readily apparent from the large standard deviation and wide range. Four factors having a strong influence on expenses are: (1) the level of care; (2) performance status; (3) family size; and (4) distance from the hospital.

You can also estimate with some accuracy the magnitude of some of the larger expense categories. For example, transportation costs can be estimated by level of care, distance from the hospital, and family size. Food expenses are predictable from the level of care, age at diagnosis, and the distance to the hospital. Miscellaneous expenses, another large part of the total, as well as the smaller categories of clothing and family care, are more difficult to predict.

The level of care was the most important factor for each category of expense. Families of children who were hospitalized for the entire week of data collection had the highest nonmedical expenses, followed by those whose children spent part of the week as in-patients. Out-patients and children who had no contact with the Medical Center during the week, had relatively fewer expenses.

The results of the loss of pay questionnaire show that half of the 32 families who responded reported no loss of pay. The rest of the families had significant losses. Half lost at least

$68.94. The other expenses for these 32 families were similar to those of the entire sample. When the loss of pay data were added to the out-of-pocket expenses, half of the families had weekly combined expenses of at least $88.20.

Another way of looking at these figures is that with half the families, the combination of expenses and loss of wages represented more that 25 percent of their weekly budget. The average for the whole group was closer to 50 percent of the weekly budget for nonmedical expenses. According to a recent article in the New York Times, the average family should spend around 5 to 6 percent for all of their income on medical expenses. Our families were spending closer to 25 percent of their family budgets for nonmedical expenses incidental to the illness of only one person in the family, and we haven't even looked at the medical expenses yet.

The results of the present study demonstrated that the out-of-pocket, nonmedical expenses associated with pediatric cancer are sizable, and can represent a significant percentage of a family's total budget. The data not only indicated the magnitude of these costs, but shed light on the factors which contributed to increased expenditures.

For obvious reasons, hospitalization, as opposed to out-patient treatment or no contact, and distance from the treatment center, were associated with higher expenses. As the disease progressed, expenses increased. Costs also increased with family size. The more children in the family, the greater is the expense of caring for them in the parents' absence.

These data deal with the out-of-pocket costs and loss of parents' wages when a child has cancer. These costs and losses of income are in addition to the financial burdens of the cost of medical treatment, which far outweigh nonmedical costs. While most families have some third-party coverage, virtually none are covered for all medical costs. When the left-over medical costs are augmented by nonmedical expenditures and the family suffers a loss of income at the same time, the result is financially devastating.

An illness should be considered catastrophic if it costs more than 15 percent of the yearly gross family income, less $50 per each family member. We have demonstrated that the out-of-pocket costs plus loss of pay have averaged considerably more than 15 percent. For half of these families, the figure was over 25 percent.

This economic impact has added a significant burden to the family's overall distress when confronted with the uncertainties of cancer in their child. Clearly, no families can pay for this kind of financial assault. Some are forced to make treatment decisions on the basis of financial hardship, and this eventuality is feared by all. Many will be faced with the possibility of bankruptcy when they are trying to assure the best care available.

Even when the financial hardship is less extreme, it has long-lasting negative effects on all members of the family. Because of the depletion of resources over an extended period, parents and siblings are deprived of basic needs as well as luxuries because such a large portion of the family budget goes toward care of the sick child. There are only limited funds available to assist with nonmedical, out-of-pocket expenses. The Leukemia Society and the American Cancer Society have been forced in the past year to limit funds to families for transportation and drugs. In some areas, there are other private funds, but no resources for most patients' families. There are no simple solutions for the financial plight of our families. Even the best social work services and financial counseling cannot locate resources where none exist.

There is hope that some of the forthcoming health care legislation will begin to deal with the medical costs of catastrophic illnesses. Clearly, nonmedical but disease-related out-of-pocket costs need similar attention.

XI. The Terminal Child, Relapse

Edwin N. Forman, M.D.

This conference has at least two very beneficial effects for me. One is, the opportunity to hear the presentations and discussions, and share what you are sharing. The other is that it has made me sit down and organize my thoughts on the subject I was assigned, come to conclusions I will share with you, and be able to hear your response. First, I would like to thank the members of my team for their help. Although I am responsible for what I say, much of it is almost verbatim from our discussions over the years. This team includes the spectrum of parents and some children, as well as medical professionals. Happily, five of our people are here today, including four parents.

As I thought about this subject, the terminal child--relapse, the overriding theme, as I saw it, was a dilemma that is really a natural part of life, but it is brought to an acute point in dealing with a child who relapses with cancer. It is the balance of hope or optimism as opposed to reality and acceptance, something which we face every single day. We are all going to die. Is life meaningful? And how do we balance the reality of the human situation with an inherent hope?

Let me go through a few simple definitions. I am not really going to be talking about the terminal child. My definition of a terminal child is a layman's definition, and it means the very end of life. Someone is terminal when he is in a coma or semi-coma, the last few hours or days of life, when he really has very little input into the decision-making about his own life, and in which a totally different type of support and decision-making is

involved. I think we are going to be hearing more about the care of the terminal child in the home setting, later this afternoon.

I don't consider the child terminal when he relapses, even if his chances for cure are now very remote, or in fact are essentially zero. All of us have learned that such children can go on in this state for months or years, and have very full lives and survive people we thought were cured. My definition of relapse is very simple. It means recurrence of clinical disease. Some children who are in complete remission obviously still have the seeds of their malignancy in them and may relapse some day. So relapse simply means a child in whom the disease becomes clinically, demonstrably evident again.

Even with that definition, there are many kinds of relapses, and all of them have different implications. Obviously, it depends upon the disease. An isolated recurrence in a Wilms' tumor may have a rather optimistic outlook. The recurrence of certain other malignancies may have a very poor prognosis, even the first relapse. Other factors obviously influencing outcome are what relapse are we talking about--the first, second, or third, and how extensive is the relapse?

However, even the first relapse of a disease that has a good second-line treatment is an overwhelming moment, certainly as devastating, perhaps even more so, than the initial diagnosis, for reasons that some of you already know. The disease is not so easily defeated as we had hoped. Our front line drugs have failed. All of the initial feelings of hopelessness, helplessness, despair, and even guilt, are brought back again, and what is worse, we, the parents and the physician, now have a keen awareness of what lies ahead. When the disease was diagnosed and you were told that treatment exists, you had no clear picture of it. At relapse, the child has already been through intensive therapy. In addition you have the added agony of knowing that the chances of success are often diminished. So, it is a tremendously painful moment in the course of the illness.

We can look at dealing with relapse through the issues or challenges it raises for a child, a parent, a family, and the physician and the medical team. I am not going to say much about the issues it raises for the child even though it is obviously an important subject.

In thinking about how people face these challenges, it became evident that the ability to deal with relapse requires a lot of pre-relapse work. It requires work during remission: work in learning about the disease, its natural history; learning about

drugs and what risks are entailed; and, establishing certain relationships and potential support mechanisms for use when the family is in trouble or the child is in trouble. This is a learning process for not only the parents and the child, but also for the physician and the medical team.

Some of the tasks are similar for these groups of people. Certainly, issues of honesty, creation of an atmosphere of openness, and acceptance of different attitudes and different desires and choices, are key areas of pre-relapse work.

As far as honesty with the child goes, this raises many concerns similar to those at initial diagnosis. I am not sure I need to dwell on them with this group. Let me simply say that I am a believer in directness and honesty. Three members of my team, a parent consultant, another physician, and I, have written a "Parent's Handbook on Leukemia"* which was distributed with other literature at this conference. Page 39 deals with those observations which show that honesty works, dishonesty is harmful, and, in fact, truth is unavoidable. I leave that reading for those of you who question this position and want to explore why many physicians have come a long way in recommending honesty with children in telling them about the disease, its name, and treatment.

I think it might interest you to see what the challenges are to a physician at the time of relapse. First, the physician must know himself. He has to know the personal meaning to him of a relapse in a child he is treating. I have come here from a medical cancer meeting where I asked my fellow pediatric oncologists, "What bothers you the most when your patient relapses?" and, surprisingly, although the answers were similar, the priorities were different. One physician said, "I feel so defeated, and that is a great problem for me. I arranged the protocol. I used every strategy I could, but I was defeated." Another felt most keenly the potential loss of a valued relationship. For physicians, there is often a difficulty with feeling helpless. That may be one of the motivations that led them into medicine.

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* Available through American Cancer Society local chapters.

A physician has to know what his weak spots are in facing relapse, so that he can get past them and deal with the family in an honest and open way. He has to have the ability at all points, but, especially here, to share in decision-making. I think at the beginning of the disease, when the diagnosis is made, it is very hard not to be the guiding light. I think that, amidst the distress and confusion, and inability to logically assess the situation, it is natural for parents, and appropriate that they turn to the physician and say, "What is best?"

With relapse, especially late relapses, it gets harder and harder for the physician really to know what is best all of the time, and he has to be able to share that. In some circumstances he has to be able to say, "Let's talk about this. It is not clear whether we should go to treatment A, with a good chance of remission but a high chance of severe morbidity, or treatment B with less of a chance of remission but a better tolerability."

Another problem for physicians is the lack of good data on exactly what the chances are for long-term benefit or serious side effects. For example, suppose a child has an osteogenic sarcoma and is treated with surgery and chemotherapy, and one year later a single lesion becomes evident in the lung. There is a way of approaching that, but I couldn't tell you precisely from the medical literature what that child's ultimate chances for cure are. I use this case to show that we haven't assembled very much of that kind of data. To date, apparently, there has not been much interest in looking at what the real statistical hopes are at later stages of the disease. Hopefully, this will be remedied by further studies. At our institution, we have begun to work in this area.

This will always be a problem, however, in that the the ground is constantly shifting. As you establish data about chances, it may quickly become outdated as new arrangements of chemotherapy or surgery change the risk/benefit factors again. So, decision-making at relapse will always be hard and difficult, even with more studies to accurately predict the future.

I think another challenge for the physician is to have developed, by this time, more sensitive or intimate knowledge of the family and of the child. One of the tasks that should have been worked on during the period of disease control was a better understanding of the family's priorities.

My final point has to do with cutting back on specific therapy. The physician has to know that a real test of his profession is in his dealing with the relapsed child and the terminal child.

Starting out optimistically at the beginning of the disease and hoping for a cure may be one part of his job, but another is the supportive care and help in decision-making on various options that occur after relapse. It is a difficult yet essential and even rewarding aspect of being a physician.

I want to turn now to some of the tasks or challenges for the parents. One is being realistic--that is, able to accept each state of the disease and the future. This appears necessary for being able to enter into intelligent decision-making and reality planning. Another challenge is adjusting to a life where, no matter which option is chosen, you are going to have to live without knowing precisely what is coming tomorrow. And this creates yet another task: being able to live from day to day in a meaningful and fruitful manner.

These are vital quality-of-life issues, and I think parents can enter into this decision-making only if they have some degree of acceptance. I think every physician has had the experience on occasion of dealing with parents who will not, or cannot, recognize the realities of a situation, and who will operate only from the position, "if there is any hope, no matter how remote or how little in actual gain, I am willing to put my child through anything." The physician may then find himself in the painful position of having to re-educate parents to see the reality of the situation, and that is hard to do at the time of relapse. It is easier if some work has been done between diagnosis and relapse, and some acceptance, not a loss of hope, but some acceptance of the full implication of this disease.

What are the values of hope and optimism? This was touched upon by the first speaker, and much of what I will say is summarized in an article in Science in June, 1978. It is obvious that from a psychological point of view, hope is a well-known essential ingredient of life, necessary for having the spirit and the psychological energy to go on actively with everyday living. And hope is often a vital component in interpersonal relationships, as in the continued full investment between individuals. For if an individual is designated as no longer having any chance, there may be a withdrawing or loss of investment by others. Parents rarely do that, but a medical team or playmates might.

There seems, in addition, to be a physical side to the value of hope and optimism. Certainly it helps in that it gives a reason to continue appropriate, specific, and supportive therapy. But for ages, there has been an interest in the connection between cancer and the mind.

I think I can be described as a relatively square doctor, meaning that, although born in Brooklyn, I "come from Missouri," and have to be convinced of something before I believe it. I refer to certain new avenues of health care, such as special diets, behavioral therapy, and others. Some of these, as yet have not developed a good, scientific basis. Nevertheless, there is growing knowledge that supports the mind-over-body postulate. As early as the Second Century, a physician named Galen suggested a connection between depression and malignancy. There is a whole host of modern studies postulating a direct relationship between repression of negative emotions, especially anger, denial, and feelings of helplessness and hopelessness, and the prognosis of a patient with cancer.

Now, how can that be? There is more and more information to suggest that the mind can influence physiological processes previously felt to be inaccessible to voluntary control. For example, there is a part of the brain called the hypothalamus, which appears able to communicate with and influence the immune system. As you may know, there is great interest in whether the immune system plays a role in the control of malignancy.

In the 1950's, a physician named William Green, in looking at patients with leukemia and Hodgkin's disease, believed that certain manifestations of the disease were related to feelings of helplessness, hopelessness, and being all alone.

At a recent meeting of the American Society for Clinical Oncology, a highly respected organization which critically reviews the reports they allow to be presented, I heard a paper by Drs. Derogatis and Abeloff. It is with some hesitancy in terms of self-protection that I tell you the results of this study. The question they ask is: Can the emotional state of a patient affect prognosis after cancer has been diagnosed? They looked at the course of women with breast cancer. Their one significant and striking finding was that women who expressed a high degree of anger towards not only their disease but their doctors did better. Phrased in psychological terms, these patients were "good at externalizing negative effects or feelings." In other words, the fighters had a better chance. Now, with modern interest in biofeedback mechanisms and behavior modification techniques, Dr. Simonton in Texas has developed a special program for patients with cancer. This is a new study, results are not yet available, and I don't know if they will be significant. But the approach is promising. He has dealt with his patients in three modes. He has involved them with psychiatric intervention in terms of their feeling about cancer. He has encouraged regular meditation to enable them to relax, and, perhaps, most

interestingly as we saw in a cartoon earlier, he has helped them visualize, in symbolic terms through drawings, medical treatment and their own white cells attacking cancer. Some of you may have seen reports of this approach. It is very experimental, and obviously needs a lot more study. But it creates a reluctance to draw away hope, not only for psychological reasons but physical ones as well. When your words or behavior communicate that the battle is lost, or probably lost, are you doing the patient a real disservice, not only psychologically but biologically?

So if relapse occurs, how does one develop a balance between an optimistic approach and a realistic approach? For me, that has been achieved through a phrase repeated many times today, namely, learning from each other. As an example, I would like to finish with a brief story about a child I was privileged to meet.

His name is Randy. He developed acute leukemia, had a remission for 3 years, followed by recurrent relapses. Getting him back into successive remissions was rather difficult and fairly toxic, and at one point if became very difficult, in fact virtually impossible to achieve a complete remission.

Now Randy and his family had been very active in trying to understand the disease and in expressing their feelings, including anger about such things as how long they had to wait in the clinic. They had already assumed responsibility for certain aspects of treatment. Randy made sure he took his Mercaptopurine and Methotrexate. At this point, I was able, along with other members of the medical team, to sit down with the family and ask, "Do we want to go for broke and wipe out the bone marrow with drugs like Adriamycin and possibly get him into remission that has a short duration, maybe a few months, at the expense of great toxicity? Or should we think about some less toxic therapy which would simply contain the disease rather than aim for a marrow remission, but possibly offer a better quality of life?" This was a decision that I didn't feel competent or capable of making alone, and it was not difficult for this family to make the decision of containing the disease with less toxic therapy. This choice proved not only successful, but taught us all a great deal.

First of all, for 6 months, on very modest intramuscular therapy adapted for home use, this boy lived a relatively normal life. I hadn't thought that was possible. Finally, the treatment began to lose its effectiveness and create undesirable side effects that Randy did not want to experience. He then helped us in the decision to switch to supportive therapy, given as much as possible at home, including, and this was a new experience for

us, platelet and other blood transfusions.

Approximately another 5 or 6 months went by, to everyone's amazement, with this boy going to school, playing, and even riding his bicycle with platelet counts under 20,000. One lesson in the story is how long and how well some children do on minimal or only supportive, or even no therapy at all. But the reason for including it in my discussion today, is to point out that this sort of decision was impossible for me as a physician to recommend to the family. It had to come out of a mutual sharing.

The optimal use of hope and acceptance, which are both essential ingredients in dealing with relapse, can best be achieved through a true and ongoing sharing of knowledge, feelings, and decision-making between the physician and medical team on one hand, and the parents, child, and family on the other. Thank you.

QUESTIONS AND ANSWERS

[Q]: In managing a comfortable relapse, are you not risking a malpractice suit? If so, do you discuss it with the parents?

[DR. FORMAN]: No, I don't think we are running such a risk. I think the question implies that in a relapse there is some standard acceptable therapy, and if you say, "Do you really want to do that, or do you want to opt for something less toxic?" you are embarking on a dangerously unconventional course. Actually, there aren't standard regimens that would stand up in court, or even before the medical experts, as absolutely the way to go for a relapse. No, that is not a concern at all.

Obviously, implicit in that approach is the relationship between the physician and the family. It is not the sort of thing you can do with a family that you don't know, and that doesn't know and trust you.

[Q]: Dr. Forman, why doesn't a doctor go to the funeral of the child he has been involved with for years? Do doctors feel that it is their failure? For the family, you, the doctor, are a part of our families throughout the years of treatment and I feel insulted when the doctor doesn't attend the funeral.

[DR. FORMAN]: I would love to hear that question answered by those of you who have lost children. Many might have a different perspective on it. I go to practically all of my patients' funerals, so it is hard for me to answer that. My associate

does, too. I do it out of my own need and not to satisfy the family. There are lots of ways to "get out" of going. Often funerals are on the busiest clinic days, and you have other children "needing you" so a physician could avoid it, or in fact be unable to attend.

[Q]: Thank you, Dr. Forman. You stress the importance of pre-relapse preparation, informing ourselves of the alternative therapies, etc., but doesn't such preparation give a lie to one of the points raised by the others? Assume the child is on the road to recovery, not relapse.

[DR. FORMAN]: The point raised by others and by myself concerns the optimistic approach after the initial obtaining of a remission, namely that the child is going to stay in remission. The question asks, if you think about the possibility of relapse, are you interfering with that road to recovery? I don't think so. It is at relapse that I encourage careful consideration of all possible therapies. I think it is necessary not to be blindly optimistic, just as it is necessary not to be totally resigned and pessimistic, regardless of the situation.

[Q]: Our teenage daughter was diagnosed with leukemia in April with a prognosis of 12 to 18 months, and died in May, 1 month later. She had granulocytic leukemia. How common is the occurrence of granulocytic, and what is its predicted success rate as compared with lymphoblastic leukemia?

[DR. FORMAN]: Granulocytic leukemia is worse, and definitely harder to treat. Ten years ago it was virtually untreatable. We have progressively made small gains. But whereas we talk about the lymphocytic type of leukemia having a 50 percent 5-year complete remission rate, no one is using these figures in acute granulocytic leukemia. It is hard to give any figures. A couple of years ago the majority of patients were surviving 1-1/2 years. One can't predict what it will be now, with new innovative therapies continously coming along. But it is definitely a more deadly disease, requires more toxic therapy, and its outlook is not as bright as that of lymphoblastic.

The danger of giving a prognosis, like "she has 6 to 18 months to live," is illustrated by that case. We had a child admitted with acute granulocytic leukemia who died in 48 hours, and on the other hand, we have another child with that diagnosis who is 6 years post-diagnosis and doing beautifully. I think it is impossible to say: "This is the way it is going to be."

XII. Home Care for the Child with Cancer

Ida M. Martinson, RN, Ph.D.

"Home Care for the Child with Cancer" is the title of a nursing research study which has been funded by the Department of Health, Education, and Welfare, National Cancer Institute, Grant CA 19490, for 3 years beginning July 1976. This was preceded by a pilot study starting in 1972.

I first became aware of the problem of home care for dying patients when my father-in-law was hospitalized in the terminal stages of cancer. My husband and I were both doctoral students in Chicago at the time we got a telephone call from my mother-in-law to come immediately to northern Minnesota to a rural hospital where my father-in-law was hospitalized. While living in Hong Kong, he had been diagnosed as having cancer at the head of the pancreas and had returned to Minnesota. We drove all night from Chicago to Minnesota. We arrived at the hospital and as I opened the door and entered the hospital room, my father-in-law said to me, "Ida, I want to go home to die." I thought for a moment and said, "O.K., we'll start to work on that." "Home" was a cabin 7 miles away from the hospital, and I did not know a lot of neighbors and resource people at that point.

What occurred in the next few days was quite interesting. I first checked with the physician, who said that if he were in my father-in-law's position, home is where he would like to be. I then contacted a public health nurse who agreed to help. The nurses in the hospital were pretty skeptical of going home because he was so sick. But there were three of us in the family

who were registered nurses, so from my point of view we could give him the required nursing care. However, it took 7 days for the younger son in the family to agree that we should bring him home. At that point I thought it was essential that all of us should agree. It was on the seventh day that the father said to the son, "I really want to go home." We got him home within 2 hours after that, and I remember as we entered the cabin, he said, "Home, sweet home."

For the next few days there were three of us nurses involved, and it wasn't too difficult. But then one of our nurses had to return to California; the other nurse, a sister, just found it too hard, and thought that we should readmit him to the hospital. So I ended up being involved 24 hours a day.

I began to see how much it meant to my father-in-law to have the grandchildren--all ages--come in and out of the room. I began to see that at home we could do things such as cook his favorite food--he loved to eat fresh beets. When he got to the point where he couldn't swallow, he would chew them and spit them out.

Days continued on. Then one morning at 2:30 I got up. It was time for his pain medication. He did not have pain, and he was more alert. Somehow I felt it was time to call everyone. I ran around to the surrounding cabins and everyone was there to be present for the last 5 minutes of his life.

Following his death, we all went into the family room, and I would say that that time we spent together as a family was invaluable. As I look back upon it now, this was the first time in my personal and professional life that death had not been frightening to me.

I then returned to Chicago and finished studies for a Ph.D. in physiology. I continued to think about the statement family members had made that the most important thing that I had done was to call everyone. I thought, "Is this something for us? Is there some way of studying the physiology of dying so those of us in the hospital would not be sending parents and relatives home and then having the person die while they were at home?" Studying the dying process is very difficult. And although I have done some beginning work in that area, I ended up becoming involved in home care for children, essentially due to happenstance.

After we had moved to Minnesota, one night I began talking to our neighbor, Dr. John Kersey, about his work. He mentioned that he was involved at that time with a family that was difficult medi-

cally to help because the child was dying. This was a family that had been trying to keep the child at home as much as possible. I said, "Well, I wonder. Do you think it might help families if they cared for the child, even through the death event, at home?" He said, "Well, you think about it." I answered back, "Well, give me 5 years. By then I'll have a whole study worked out." Would you believe it, the next day I got a telephone call. Dr. Kersey had told this family about me--not about the dying at home part--but that I was interested in helping families at home. I couldn't refuse, and so I got involved on Saturday morning, 17 days before Eric died. At the time of one of the first home visits, I brought up the possibility of caring for Eric all the way through death. The parents said, "No," they couldn't do that but they would like to care for him as long as possible. I said, "O.K., let's find out how long it can be." I thought it would be important to find out under what conditions and when it is essential to admit a child to the hospital. I didn't know what I was getting into. I don't think the family did either. But we cared for Eric and he did die at home.

My involvement with home care then continued over the next 5 years during which time we worked with eight families--five of the children dying at home. It was during this time I got to know Dr. Mark Nesbit, professor of pediatrics at the University of Minnesota. He first became aware of our work when parents came to him for the autopsy report, and he found for the first time that parents were mentioning something positive that had happened at the time of death.

As a result, we wrote up the experiences with the eight families as a pilot study for a research grant proposal to the National Institutes of Health. I thought it would go to the Nursing Division, but instead it was sent to the National Cancer Institute. Even though I received word that NCI had approved it, I'll never forget the day I got the telephone call indicating that I had also received the money.

Two questions in the presently funded study are: (1) Is it feasible to have a child die at home? and (2) Is it desirable?

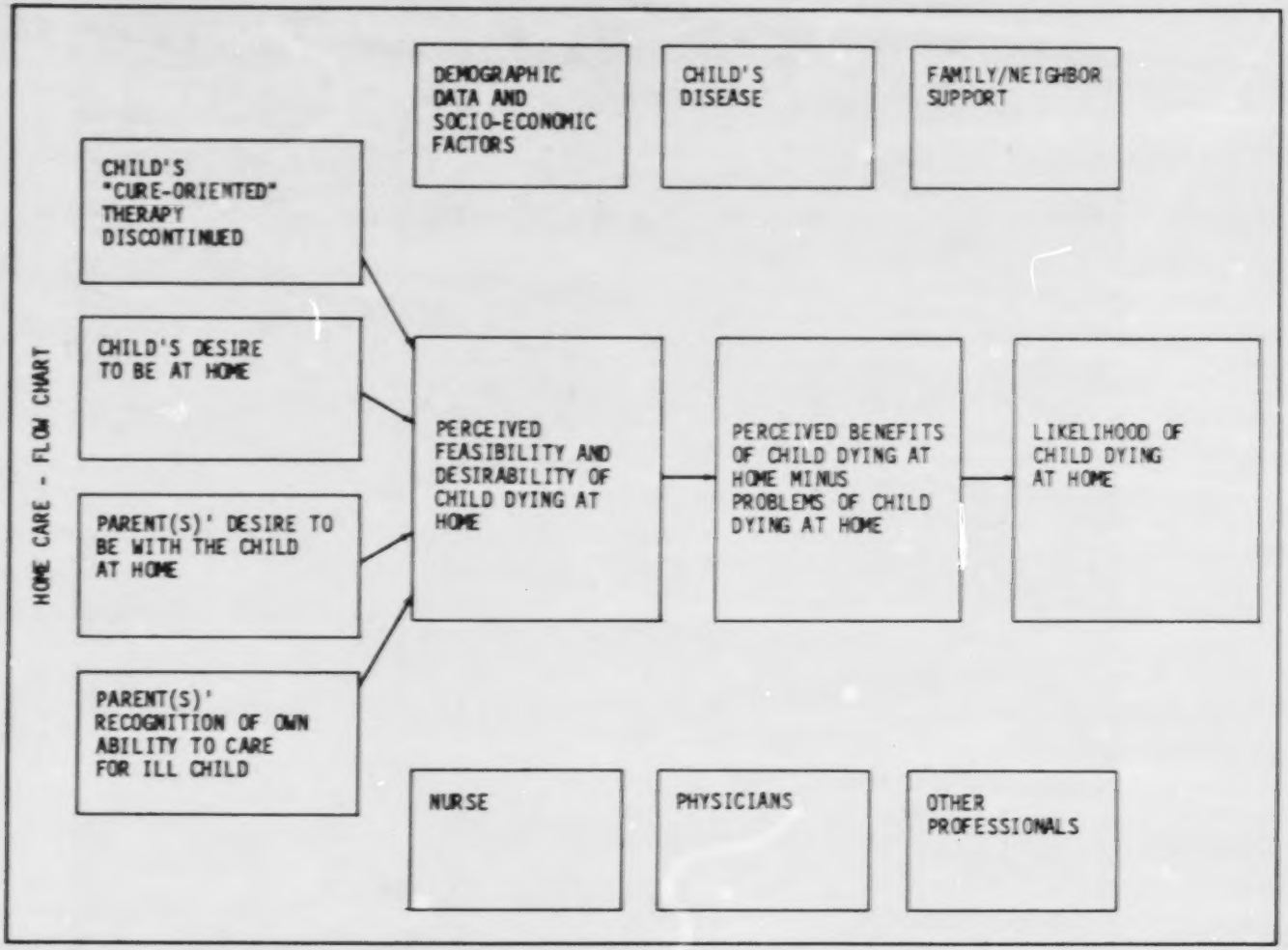
HOME CARE - FLOW CHART
DEMOGRAPHIC DATA AND SOCIO-ECONOMIC FACTORS
CHILD'S DISEASE
FAMILY/NEIGHBOR SUPPORT
CHILD'S "CURE-ORIENTED" THERAPY DISCONTINUED
CHILD'S DESIRE TO BE AT HOME
PARENT(S)' DESIRE TO BE WITH THE CHILD AT HOME
PARENT(S)' RECOGNITION OF OWN ABILITY TO CARE FOR ILL CHILD
PERCEIVED FEASIBILITY AND DESIRABILITY OF CHILD DYING AT HOME
PERCEIVED BENEFITS OF CHILD DYING AT HOME MINUS PROBLEMS OF CHILD DYING AT HOME
LIKELIHOOD OF CHILD DYING AT HOME
NURSE
PHYSICIANS
OTHER PROFESSIONALS

FIGURE 1

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To answer these questions (Figure 1), we consider the following points when families are referred to us:

(1) Discontinuation of the child's cure-oriented therapy. I think none of us wanted to get into a situation where home care would be an alternative to therapy. So children at the time of referral to us have usually been through the last experimental protocol.

(2) The child's desire to be at home. We have yet to find a child who does not want to be at home, but I think that it is still important for us to ask the child. There might be a child who really has become more dependent upon health care in the hospital and would prefer to be in the hospital.

(3) The parents' desire to be with the child at home. This is a less important factor than we thought it would be. Essentially what we are finding is that the parents are willing to provide home care because of the child's desire to be at home. The child's desire is far more important. If you ask a parent, "Do you want to take your child home to die?", they are probably going to say "no." They don't even hear the words, "at home." They are saying, "No, I do not want my child to die."

(4) The parents' recognition of their own ability to care for the child is the most crucial point. We have yet to find parents who do not have this ability, but we do have parents who do not recognize their own ability to care for the child. And this would be a basis for another study: what are the factors involved; what happens to parents' recognition of their own ability when they are involved in our health system year after year?

We then move into the situation of "perceived feasibility and desirability of the child dying at home." At this point in time, we have not said "no" to anyone. We have accepted all referrals. We're studying the roles of the nurse, the physician, and other professionals, including the clergy. We're getting demographic data, history of the child's disease, and attempting to identify family and community support.

Moving into the next stage, we're beginning to see that it's the ratio between the perceived benefits of a child dying at home minus the problems of the child dying at home. Frequently, the professionals involved count up the problems and sometimes they

reach a point where the problems are so many and of such magnitude, that it is felt it is necessary to admit the child to the hospital. At this point parents are usually quite articulate as to the benefits of home care from their point of view.

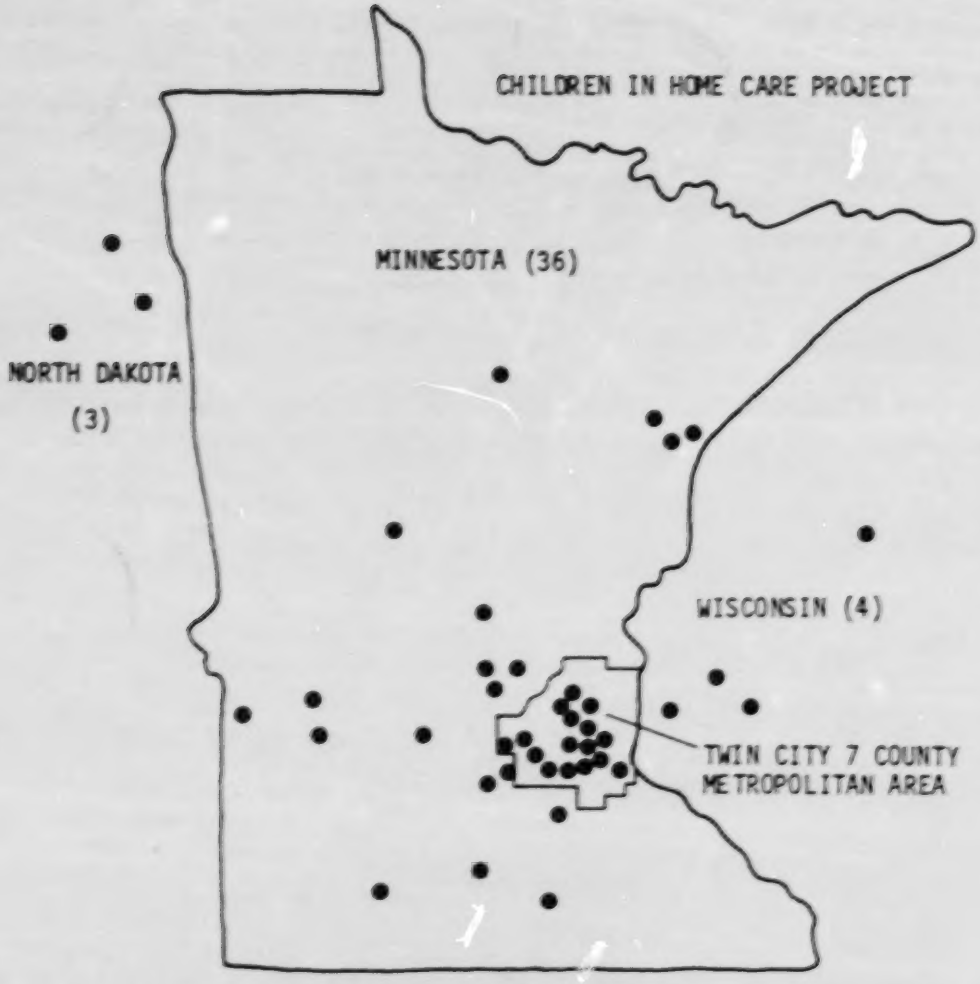
FIGURE 2

NUMBER OF CHILDREN WHO HAVE DIED
WHILE PARTICIPATING THROUGH DECEMBER, 1977

Died at Home	36	(84%)
Died in Hospital	7	(16%)
Total	43	(100%)

Figure 2 summarizes data from the first 18 months of the study--through December 1977. We had worked with 43 families where the child had died; 36, or 84 percent died at home and 7, or 16 percent in the hospital. This really has surprised me. I had predicted 50 percent would die at home and 50 percent in the hosptal.

FIGURE 3



Where do these children come from? As you see (Figure 3), quite a few of them are from the Twin City-Seven County Metropolitan Area. But, we serve all of Minnesota, and have had some families in North Dakota and Wisconsin.

FIGURE 4

SOURCE OF REFERRALS
(N 43)

HOSPITAL

From University of Minnesota Hospitals	24	56%
From Eight Other Hospitals	19	44%
Total Number of Referrals	43	100%

REFERRING PHYSICIANS

From University of Minnesota Hospitals	9	56%
From Eight Other Hospitals	7	44%
Total Number of Physicians	16	100%

Where are our referrals coming from (Figure 4)? From the University of Minnesota: 24, or 56 percent; eight other hospitals: 19, or 44 percent. But through word-of-mouth, other hospitals have heard of our project and also have made referrals. At the University of Minnesota we have worked with nine physicians. Seven additional physicians represent the eight other hospitals in the area.

FIGURE 5

AGES OF CHILDREN WITH CANCER

DIED AT HOME
(N=36)

Mean.....8.9 years
Median.....8.5 years

Range...1 month to 17 years

AGE (years)	NUMBER	%
2 or less	6	17
3 to 5	8	22
6 to 8	4	11
9 to 11	4	11
12 to 14	4	11
15 to 17	10	28
	36	100%

The ages of children with cancer who have died at home while they were a part of our study, through December 1977, are shown in Figure 5. We found a mean age of 8.9; median of 8.5 with a range of 1 month to 17 years. The 1-month-old child had a congenital leukemia. Looking at the ages raises the question: Is there some age where it is more feasible to care for the child at home? The answer could well be the adolescent. In the group of 15- to 17-year-olds, some thought the children would not want to be at home. As you can see in Figure 6, however, that has been the largest single group dying at home. With such a small number of rehospitalizations, the rehospitalization does not seem to be related to age.

FIGURE 6

AGES OF CHILDREN WITH CANCER

DIED IN HOSPITAL
(N=7)

Mean.....9 years
Median.....10 years

Range...4 years to 14 years

AGE (years)	NUMBER	%
2 or less	0	--
3 to 5	2	29
6 to 8	1	14
9 to 11	2	29
12 to 14	2	29
15 to 17	0	--
	7	101%

FIGURE 6

FIGURE 7

DIAGNOSIS

CHILDREN WHO DIED AT HOME	7 - acute lymphoblastic leukemia 8 - acute non-lymphoblastic leukemia 1 - congenital leukemia 4 - Ewing's sarcoma 4 - neuroblastoma 2 - ependymoma 2 - brainstem glioma 1 - astrocytoma 1 - medulloblastoma 1 - malignant terratoma 1 - Burkitt's lymphoma 1 - lymphoblastic lymphoma 1 - rhabdomyosarcoma 1 - osteogenic sarcoma 1 - malignant histiocytosis
CHILDREN WHO DIED IN HOSPITAL	4 - acute lymphoblastic leukemia 1 - undifferentiated lymphoma 1 - Hodgkin's 1 - neuroblastoma

Diagnoses of the children covered a rather wide range (Figure 7). We had decided we would not limit our feasibility of home care study to leukemia patients. Any child with cancer under the age of 18 who has been referred to us was accepted in the study. At this point, we are unable to say that there is any one type of cancer that cannot be cared for at home and another that can. It has been possible regardless of the type of cancer.

FIGURE 8

OCCUPATIONAL GROUPING
OF HEAD OF HOUSEHOLD

GROUP	CHILD DIED AT HOME		CHILD DIED IN HOSPITAL	
Welfare	1	3%	0	--
Labor, unskilled	10	28%	1	14%
Labor, skilled	6	17%	3	43%
Farmer	4	11%	2	29%
Nonprofessional	9	25%	1	14%
Professional	6	17%	0	--
Totals	36	101%	7	100%

We have looked at the occupational grouping of the head of the household (Figure 8). In the pilot study most of our families were professional families in higher socioeconomic classes. In the present study, we had one family on welfare; ten heads of household were unskilled laborers; six were skilled laborers; four were farmers, nine were nonprofessional workers; and six were professionals. There seems to be no relationship between level of occupation and ability to effectively care for the child at home.

FIGURE 9

EDUCATIONAL LEVEL
OF THE 62 PARENTS OF THE 32 CHILDREN

No High School Diploma..... 5
High School Diploma.....41
College Degree.....16

The educational level of the parents has been tabulated for the first 12 months of the study only (Figure 9). Five of the parents have no high school diploma; 41 have a high school diploma; and 16 have a college degree. Again, home care did not

seem to be related to the educational level of the parents, but rather participation in the project represents the population that the hospitals are serving in our area.

FIGURE 10

PAIN MEDICATIONS

(Given during last 48 hours of life)
36 patients who died at home

None	6
Oral or Rectal	23
Injectable	7

Looking at the pain medications (Figure 10) given during the last 48 hours of life for the 36 patients who died at home, we have had six children who apparently had no pain. Most of the children, however, did have pain. Pain control is an important element in the feasibility of home care. Parents have also commented that their child has had more pain relief at home than in the hospital.

We had considerable trouble trying to control the pain of one of the children early in the study. The physician involved contacted the Seattle Pain Clinic who suggested the use of methadone. It worked so well with that first child that we have continued to use methadone for children with severe pain. It is as effective as morphine sulfate and had other advantages for us. It is effective for 8 hours. If you have a child who has pain relief for 8 hours, you have the potential of the child sleeping through the night, which in turn allows the parents to sleep through the night. I think it is apparent that allowing parents to get sufficient rest can be a critical variable in whether parents are able to keep their child at home.

Of the seven children who received injectable medications, the parents of six of these children were successfully taught how to give injections to their child. One parent, who tried to learn to give injections using an orange, and on others, just could not give one to her own child. For this child, the nurse made a home visit when the child needed the injectable medication.

FIGURE 11

HOSPITAL ORIENTED EQUIPMENT
(N=36)

Oxygen equipment	5
Intravenous equipment	4
Indwelling urinary catheter	2
Texas urinary catheter	3
Gavage feeding tube	1
N-T suction machine	3
Wound drainage tubing	1
None	22

When we started the program, one of the things we wanted to do was to make sure we could give the quality of care that the child would have in the hospital. We didn't say "no" to any hospital-oriented equipment. We really thought that it was important to attempt to bring whatever was necessary to the home (Figure 11). We did have five children who needed oxygen, essentially for comfort. We knew from the literature that parents of children with cystic fibrosis have for years been handling oxygen tanks at home, but what about a family with the acute crisis of a dying child? Would they be able to remember all the safety precautions, for example? I can remember that first family and how closely we supervised them when the oxygen was in use. I think that the motivation of these families is so high that they have not had difficulties in learning the safety techniques of any of the hospital-oriented equipment.

Four of our children had to have intravenous equipment. When we began over 1-1/2 years ago, we found that public health nurses, because of certain rules, could not supervise an IV at home. We thought about it, discussed it, and then decided to supervise the IV's ourselves. Because of our experience in this area, several of the public health nursing rules and regulations have been changed to allow their nurses to supervise an IV at home. It is interesting to note that parents frequently counted the drops and occasionally changed the bottles for the IV while the child was in the hospital. Other hospital-oriented equipment included the in-dwelling urinary catheter, Texas urinary catheter, gavage feeding tube, wound drainage tubing, and an N-T suction machine. The suction machine was one that bothered me personally. I thought, "That will be one for sure that will have to be done in the hospital!" However, we have had three children who have

required suction and the families were able to successfully perform this task at home.

Finally, out of 36 families, 22 of the children required no hospital-oriented equipment. I think that really surprised us, because we were prepared and willing to bring all these things into the homes as necessary.

FIGURE 12

HOSPITAL ORIENTED FURNISHINGS AND SUPPLIES
(N=36)

Wheelchair	9
Overbed table	7
Hospital bed	5
Lamb's wool	12
Chux, ABD pads, etc	13
Flotation pad	9
Alternating air mattress	4
None	8

Then we looked at the hospital oriented furnishings and supplies (Figure 12). Nine of the children used wheelchairs; seven used overbed tables. However, one mother commented, "Now, Dr. Martinson, why bring me an overbed table? An ironing board works much better, and besides, it doesn't look like the hospital." Five families had a hospital bed. In the pilot study most of the families had a hospital bed, but we found a wheelchair was perhaps more useful. After obtaining a hospital bed for one child, the next week the mother came back and said, "Oh, could I have a wheelchair instead?" We got the wheelchair and she later said, "We were able to take our child camping over Labor Day weekend." Other families had similar experiences: "He was able to be with his father, who is a mechanic, during the hours that he was feeling good." "I was able to take her grocery shopping. She can't talk any more, but she can nod her head at foods she wants me to buy." These experiences point to another whole area to look at: the type of activity that a child can participate in during the days and hours before death.

Other hospital-oriented furnishing and supplies included Chux, ABD pads, etc., for 13 families; nine flotation pads, four alternating air mattresses. Here again, eight of the children did not require even these supplies or furnishings.

Length of home care involvement for the 36 children varied from less than 1 week to over 3 months (Figure 13). With 10 families, it has been less than 1 week. This points to the necessity of moving quickly. If a decision is made to send a child home from the hospital on Friday, you don't wait until Monday to contact a nurse to help the family. For five families, involvement was 1-2 weeks; for six families 3-4 weeks; for 13 families 1-3 months; and for two families over 3 months. Our longest involvement with any family was 104 days.

FIGURE 13

LENGTH OF HOME CARE INVOLVEMENT THROUGH DEATH
(N=36)

<1 week	10 families
1-2 weeks	5 families
3-4 weeks	6 families
1-3 months	13 families
>3 months	2 families

Place of death for the children has been the living/family room for 26 children, and the bedroom for 10 children. One of our pediatric oncologists felt this data convinced him more than anything else of the value of home care. This demonstrated the type of family involvement that home care represents. We asked the families of these 26 children why the child died on the sofa or bed in the living room or family room. Usually the answer was the child wanted to be there. As one mother stated in a post-death inteview, "Every time I would move my legs when I was sitting with him in the hospital, my son would say, 'Don't leave me, Mom.' When I got him home, I was even able to be upstairs because he was on that sofa and in the center of family activities." Words just don't always describe things, but I think more and more I am seeing that these children are living at home in a very full and meaningful way, up to that moment of death.

FIGURE 14

DIRECT PROFESSIONAL NURSE INVOLVEMENT
FOR THE 27 CHILDREN WHO DIED AT HOME

	NUMBER PER FAMILY	TOTAL HOURS PER FAMILY
HOME VISITS	Mean.....11.4 Median..... 8 Range.....1 to 46	Mean.....26.2 Median.....15.3 Range....2 to 120
TELEPHONE CALLS	Mean.....26.2 Median.....18 Range....0 to 101	Mean..... 7.0 Median..... 3 Range.....0 to 23.5
TOTAL DIRECT INVOLVEMENT		Mean.....30.6 Median.....18.8 Range....3 to 143.5

Now, what did it take as far as direct professional nurse involvement for the first 27 children who died at home (Figure 14)? (These figures, again, are for the first 12 months only.) Number of home visits per family was a mean of 11.4, a median of 8 and a range of 1 to 46 home visits; total hours per family was a mean of 26.1, median of 15.3 and a range of 2 to 120 hours. Telephone calls were a mean of 26.2, median of 18 and a range of 0 to 101. Total hours involved for telephone calls were a mean of 7.0, a median of 3.0 and a range of 0 to 23.5 hours. We have found using beepers for our nurses has been helpful.

Total professional involvement time was a mean of 30.6 hours; a median of 18.8 hours and a range of 3 to 143.5 hours.

FIGURE 15

AGE AND EXPERIENCE OF HOME CARE
PRIMARY OR COPRIMARY NURSES

AGE (N 46)

Mean	36.9 years
Range	24 to 63 years

TIME SINCE RECEIVING R.N. (N 46)

Mean	14.6 years
Range	1 to 44 years

For the 43 children involved, 46 primary or coprimary nurses served (Figure 15). In several instances a nurse could not give a 24-hour commitment to the family and we then had a coprimary nurse who took over the commitment when she was not available. Average age of the nurses was 36.9 years, with a range from 24 to 63 years. Time elapsed since receiving her diploma or degree was a mean of 14.6 years with a range of 1 to 44 years. We are really thankful for the nurses in the community who are willing to respond to our request for help, frequently on very short notice.

FIGURE 16

EDUCATIONAL LEVEL OF 46 HOME CARE PRIMARY OR COPRIMARY NURSES FOR 43 CHILDREN

HIGHEST DEGREE OF REGISTERED NURSES		
Master's	7	15%
Baccalaureate	21	46%
Associate	1	2%
Hospital Diploma	13	28%
Not R.N.	4	9%
Total	46	100%

FIGURE 17

COMPARISON OF BASIC COSTS FOR HOME AND HOSPITAL CARE

	DURATION OF FINAL CARE (days)	COST ESTIMATE
HOME CARE GROUP (N=36)	Mean.....32.4 Median.....21 Range.....1 to 104	Mean.....$ 810 [1] Median.....$ 633 Range..$65 to $ 2,620
HOSPITAL CONTROL GROUP (N=22)	Mean.....29.4 Median.....21.5 Range.....1 to 89	Mean.....$ 5,880 [2] Median.....$ 4,300 Range.$200 to $17,800

[1] Based on the cost of nursing services at the rate of $10/day to be on call 24 hours a day and for telephone consultation, $45/home visit and $10/clinic visit.

[2] Based on the cost of nursing services and room and board at the rate of $200/day.

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The educational level of these 46 nurses has varied (Figure 16). Since this is a research study, we attempted to get nurses with a master's degree because of the need for intensive data collection. However, in Minnesota only, 3 percent of our nurses have their master's, so we did pretty well in getting seven nurses or 15 percent with a master's degree. Twenty-one or 46 percent have a baccalaurate degree; 1 or 2 percent had an associate degree, 13 or 28 percent had a hospital diploma. Four, or 9 percent were not registered nurses. Three of these four were licensed practical nurses and one was a nursing student. With the latter, we were able to have a faculty member supervise her work and it worked out very well. For most of the nurses, it was their first time caring for a child dying at home.

For a comparison of basic costs for home and hospital care we will look at the number of days of final care (Figure 17). For our home care group of 36 children, the average number of final days has been 32.4, with a median of 21 days, and a range of 1 to 104 days. For the hospital comparison group, we used the University of Minnesota Hospitals and received a list from their computer of 22 children who had died in the hospital. We went back 3 years to get the 22 because since our project started, fewer children have died in the hospital. Here we found an average of 29.4 days of hospitalization before death, which is very close to the 32.4 days for home care. The median was 21.5 days versus the 21 days for home care; and a range of 1 to 89 days in the hospital compared to the 1 to 104 days in the home. Essentially the time lengths were the same.

FIGURE 18

COMPARISON OF BASIC HOSPITAL COST AND ACTUAL TOTAL HOSPITALIZATION COST
(N=22)

NURSING SERVICE, ROOM AND BOARD	ACTUAL TOTAL HOSPITALIZATION
Mean.....$ 5,880	Mean.....$13,016
Median.....$ 4,300	Median.....$ 8,326
Range..$200 to $17,800	Range...$68* to $58,833

*Died in the Emergency Room.

The cost estimate for home care was a mean of $810, a median of $633, with a range of $65 to $2,620. These figures (Figure 18), are based on the cost of nursing service at a rate of $10 to be on call 24 hours a day and for telephone consultation, $45 per home visit and $10 per clinic visit. Both public health nursing agencies and hospital home care services in Minnesota are presently charging $35 per home visit. It may be that we are overestimating the cost of home care, but I'd rather err on the high side.

The hospital control group had a mean cost estimate of $5,880; median of $4,300; and a range of $200 to $17,800. Those figures are based on the cost of nursing service and room and board at the rate of $200 per day, which is about the cost in Minneapolis today.

The actual hospital cost figures are considerably different. Instead of $5,880 which is the base cost estimate, the actual cost of hospitalization for the 22 children in the control group was a mean of $13,015; median of $8,326; and a range of $68 (this for a child who died in the emergency room) to $58,833. There are always four major participants involved in home care. The child, the family, the nurse, and the physician need to know that home care is feasible and that home care may well be desirable. They must also realize that pain and other symptoms can be controlled at home as well as in the hospital. There is involvement between parents and child. The parents are the primary care givers and it is important for them to realize this. The nurse has been a facilitator and the physician has been a consultant.

With our 32 families in that first year, we have now completed interviews with the families 1 month post-death; 6 months post-death, some at 1 year post-death (these will be completed by the end of the second year); and we plan to followup with another interview at 2 years post-death. All of the parents of the children who have died at home have said, "Yes, we would do it again."

The nurses involved in home care have said they would do it again. Most of them, whether they are public health or hospital nurses, feel that on the whole it has given them a different outlook toward home care. Few of them had ever been on call 24 hours a day, 7 days a week before this experience. They have found it tougher in some ways, and yet at the same time, they have been willing to do it again. One nurse summed it up: "Any doubts I had about the wisdom of caring for such a critically ill child was erased in that last hour. This is what the child wanted and we did it." I also think it's that "we did it" sense

of accomplishment that we are hearing from the parents.

The physician response has been good. Remembering that this work was started back in 1972 with my neighbor, Dr. John Kersey, and it involved getting to know other physicians before I began the funded project, much ground work had been done. The physicians now have come out strongly in support of having this service institutionalized as part of the University of Minnesota Home Health Services Department. That institution has already begun providing services, as well as St. Louis Park Medical Center in Suburban Minneapolis. Children's Health Center of Minneapolis will begin their program in June 1978. Public health agencies in the seven-county metropolitan area also have agreeed to provide home care services.

In conclusion, I express my appreciation to the grant staff members who participated during the first year and a half of the project: Gordon Armstrong, Evangeline Gronseth, Dorothy Geis, Mary Ann Anglim, and Helen MacInnis, and also to Dr. Mark Nesbit and Dr. John Kersey who served as medical consultants.

QUESTIONS AND ANSWERS

[Q]: Did the mother of the one child who was born with cancer have it herself or show signs that cells were abnormal?

[DR. MARTINSON]: No. The mother was fine. It was a real shock to her to find out the bad news when her child was one month old. That was 2 years ago. She has had a second child, a baby boy, the second baby is fine.

[Q]: There are a number of questions addressed to Dr. Martinson that deal with siblings. Does your followup cover the reaction of siblings to death at home, especially if there is a crisis, and do you have any special feelings about it?

[DR. MARTINSON]: Looking back, I wish we could start over. I would have taken a much more controlled look at the siblings. But in the beginning we didn't realize we would be working with so many families. Now we have interviewed over 20 siblings, and essentially the picture we are getting is that they were all very frightened of having their sister or brother die at home. However, after the death they said it was not frightening at all, and in reality very few of the siblings have been present at the moment of death. More often than not, they are at school, sleeping, or out playing. However, a few families deliberately

wanted the siblings to be home. They were either brought in from outside or returned home from school, and with these siblings, the attitude toward death seemed to be a very natural thing.

[Q]: I think you have already answered it, but are there any statistics concerning traumatic effects on siblings who have seen their brother or sister die?

[DR. MARTINSON]: That is a very difficult question. We don't even have statistics on the traumatic effect if a brother or sister dies in the hospital. So I think we need to study both hospital and home situations.

There are some other ways to obtain this information besides interviewing family members. I think we need also to look at the attendance and other school records of siblings so we can start to develop a data base.

The feeling is that siblings are more afraid of the unknown than are parents. In one way having the child home is more of a reality for them than for parents. We have had siblings as young as 5 years old, say that they were glad to be home because they could play with the brother or sister who died for those few minutes when he was feeling good. But they also say it was tough. They saw that their mother and father worked very hard in caring for the ill child. It is not all roses, from a sibling's point of view, to have that child at home. Yet at the same time they also will mention the positiveness of being able to do things for this child.

[Q]: What was the reaction of younger sibs, 3-, 4- and 5-year-olds, to an older brother or sister who died at home? Did they find it distressing in spite of all of the support and help offered?

[DR. MARTINSON]: The one age we still really worry about is 5- and 6-year-old siblings. At that age, they are almost at that period of magical thinking, and parents need to pay special attention. Several of our families had a sibling at that stage, and we found a commonality. The children seem to remember a time when they got angry at that brother or sister who died, and felt that they had caused the death of the child.

So, I think that although it is hard for parents to have the other brothers or sisters talk about that child who has died, it is important that parents do deliberately take time to handle some of these false notions.

[Q]: But is that any worse with a death at home than in a hospital?

[DR. MARTINSON]: That's right. I don't think it is. But we are missing, again, data in that area.

[Q]: I think that covers the range of questions in that area. Other questions deal with the breakdown in relationship of the patient and physician when a patient chooses to die at home. How do physicians seem to be handling this separation along with the guilt or feeling that they have avoided the patient at a time of greatest distress?

[DR. MARTINSON]: I did something lucky, I think. In this pilot study phase (between 1972 and 1976) I refused to take a referral from the physician unless he agreed to make a home visit. So I think that was the beginning of having the physician realize that I was not about to take over.

During that time, it turned out it was not necessary for that many physicians to make a home visit, so since 1976 we have not had that requirement. However, we strongly urge the physician to call the home. In fact, if our nurse reports that a family is beginning to wish they could hear from the physician, we will call the physician and request him or her to telephone the family. I think that has done more than anything else in continuing the relationship. I do think that this is an important area, and if you want this to be ongoing and available in the future, all need to be aware of keeping that communication going.

[Q]: What is the percentage of patients dying from infections rather than the disease?

[DR. MARTINSON]: One would need results from autopsies. Data are in the process of being analyzed. Existing data indicate that frequently the respiratory center is affected. There is really a loss of consciousness at that moment and a stoppage of breathing, so the physicians who have been contacted at this time feel it is a respiratory arrest.

[Q]: What is the percentage of bodily dysfunctions due to the effect of drugs?

[DR. MARTINSON]: Well, this is very involved. The children essentially are on pain control drugs. We certainly have had children, though, who have paralysis resulting from the disease.

[Q]: Has third party payment been possible for terminal care of

a child?

[DR. MARTINSON]: I am so glad for that question. You know you never realize what you are getting into when you start. We have the results of a questionnaire sent to the 20 largest health care underwriters in Minnesota. As it turned out, 100 percent of these companies would cover if a nurse provided daily care, but when we said the nurse only taught care to parents, and assessed the child, coverage dropped to 50 percent of the companies.

In these past 2 years, because we have been Federally funded, the home care services have been free to the participating families. There has been no submission to insurance companies as of May 1. Since we started institutionalizing the services, requests are being sent to insurance companies, and I just cannot wait to see what my data will be one year from this time. Blue Cross-Blue Shield has said they hoped by summer to come up with a national protocol or model that can be developed. I believe already Rochester, New York, has come out saying they will cover 24-hour care, 7 days a week.

There is progress being made. We need a lot of pressure on the system. If any of you are members of labor unions, that is a good way to go, because there are large numbers of people involved and they negotiate for health care coverage. When you do that, be sure home health care is covered. Presently in Minnesota it is necessary from a legal point of view to offer home care, but in labor negotiations, that aspect of home care coverage is ruled out. Insurance companies assure me that they are willing to cover home care if it is negotiated into a contract, but I think if most of us would check our own insurance policies, we probably are not covered for home care.

[Q]: Why do you use medical treatments, IV, feeding tubes, when your goal is a painless, dignified death?

[DR. MARTINSON]: I think it becomes necessary. For example, oxygen can provide needed comfort for the child. But it is not just part of a routine. It is being provided only when it is necessary for the comfort of the child. I believe three of the IV's, for instance, were necessary for seizure control. That was a pretty scary business from my point of view. Again, we found out these parents take this seriously and do an excellent job of supervising the IV's. We have only had one case where it was necessary for a hydration problem, -- dehydration and an IV was given. It looked like the child could very well be thirsty, and this eased that discomfort.

I think we must not rule out these things for a comfortable death. It opens up this whole area of comfort care. For example, one child who had mouth sores, wanted to eat Italian spaghetti. I first said, just soft foods. But the child at this point wanted Italian spaghetti, and I think it was most appropriate he got Italian spaghetti. So it is those types of issues we need to think about.

[Q]: Were injectable medications given to children with low platelet counts or how was their severe pain controlled?

[DR. MARTINSON]: We essentially tried to have pain even the severe pain, controlled by oral medication as long as possible. However, when the child cannot swallow, it becomes essential to give injections.

[Q]: When the cancer teams use the people that have been close to the family throughout the illness, much of the support is not medical but the type that could be handled by lay persons.

[DR. MARTINSON]: There are two aspects to that. I think, first, it is excellent if that team can deal with a family all along. However, we are working with families 400 miles away, a distance too far for any team to go. We have found that a total stranger, even if only there for 2 days, with the necessary nursing expertise has met the needs of the family and developed some long-lasting friendships. We have to realize continuity of the same personnel is excellent, but more important is continuity of care, and a stranger can come in and fill the role. There is a real role for the lay person.

A mother suggested to me recently the idea of having one family that has perhaps gone through this before, to come in and help a family worn down with caring. I agree we do want lay involvement and am urging the three institutions to make use of volunters as well as parents who have been through it.

[Q]: Do you agree that when it is impossible for the child to be cared for at home, that it is very important to encourage the family to be with the child at all times in the hospital? My son died in a hospital in my arms, with his father, brothers, and sisters holding his hands. We all shared this total act of love. During his last week, if one of us had to go home for any reason, another member of the family was present. My own feeling is that for total peace of mind this is necessary.

[DR. MARTINSON]: Right. I certainly think that is really important, to have someone there. As we think about a child, he

certainly would want someone with him, and I think it really important that we all make hospitalization available for children, too. I would not want hospitals or insurance companies saying that you cannot admit a child at this point. We are trying to work for alternatives. I would say from a child's point of view, it is very important that there be someone present with that child.

Parental Experiences with Dying Children

Home Care

[MS. MONTGOMERY]: My name is Kathy Montgomery, and I am here from Minnesota. My husband and I participated in the home care project that Dr. Martinson presented, and there are a number of people here who wanted to make some comment in relation to home care. I think I will begin with comments from Emily.

[MS. KULENKAMP]: I am Emily Kulenkamp. We were the first family that Ida dealt with in home care, before there was a project. Our doctor was talking with her regarding the project. Our son was diagnosed with ALL in August of 1970. In August of 1972, after three central nervous system relapses, he was off treatment. Seventeen days before his death on November 21, Ida came to our home.

Our intention at that time was to keep Eric at home. He had not been hospitalized for 6 months since his last relapse. I was to care for him to the end. Ida brought this possibility up. It was practically repulsive to me at first. I was scared out of my mind. I had never seen anybody die before, but we just kept going with the intention of keeping him at home as long as we could make it. As it turned out, we did make it through the end. I was with him, holding his hand as he died, and somebody mentioned yesterday, that for the child's sake, it is nice that the parents are present. I also believe for the parents' sake it is important to be with their child. For me, it is a beautiful memory to have been with my son, to have done what I could, and this is something I will never forget. It could also have been done in the hospital.

There have been a lot of questions about siblings and home care. I believe that there are negative effects on siblings because of the illness and death, home care, or not. Home care has the same advantages for the siblings that it does for the patient and for the family. They are all together at home, as close to their usual lifestyle as possible, and this is good.

I was there when my daughter came home from school with her milk and cookies. I was there to tuck her in bed as well as my son, and I think this was a big plus. To me, it was easier having him at home than going to the hospital.

Another question that often seems to be raised is the death event itself. As I told you, I was scared, but I think in most cases that I know of, it has not been catastrophic. It has been

peaceful. We were warned ahead of time of all of the terrible things that could happen, and they did not.

I had two questions yesterday about why the home care program did not use the Brompton's mixture. I asked Ida about this, and she told me that first of all, methadone was available. The program had started using methadone. It was successful, so they continued with it. Also, it can be given orally or by injection. My son was unable to take anything orally, so an injection was needed.

[MS. REYES]: I am Karen Reyes, and I am from Marshfield, Wisconsin. We did not participate in any program in particular. Our child lived just about 2 years, and all along I kept saying I really wanted to have her home as much as possible, and the same thing for treatments. When different things could be given at home, we took her home rather than stay in the hospital the full length of time. She did live a very full life with her disease as long as she had it. We are very happy for that.

We took her to the hospital with a very bad nose bleed. They asked, "Do you want her to stay here?" We said, "No," and the doctor said, "I really think this is going to be the end," and we kind of felt it was going to be the end, too. And the child said she wanted to go home. She didn't want to go to the hospital any more.

So, we took her home, and she was with the family. During the day, she got up and played. That was fine. The other kids were there. The dog was there. He sat by her side. He licked her. He seemed to know, because the usually active dog just sat there during those days. The friends of the other kids came over and took them to school, and so on and so forth. The next daughter to her was 6 years old, and they shared a room together. Every night she wanted Carla in her room, in her own bed, along with her. Sometimes during the night she would end up in our bed. During the day she was downstairs, and at night, back to her bed.

Oral medications wouldn't work so we were on morphine, and I think the day she died, we gave her a shot in the morning. About 2:00 in the afternoon she kind of went into a coma. It was very peaceful. She stayed in the coma until probably around 10:00 at night, when she died, and it was very peaceful. We did not find any ill effects from having it at home versus in the hospital. We saw no effect on the siblings.

[MS. KEYSER]: My name is Marty Keyser. I come from outside of Philadelphia. There was no program like Dr. Martinson's there,

but when the time came, our doctor said, "There are no more drugs. The hospital at this point will not give blood, will not give antibiotics. How do you feel about going home?" At first I felt, "You don't want me around, right? You are rejecting me." And then I started thinking about how when we left the hospital from a regular admission, Sam would start clapping, so I thought maybe it was a good idea. We went home, and I realized there are so many more possibilities at home than stuck in that little room with all of the people racing in and out. You don't have to eat breakfast at 7:00 a.m., and you don't have to consider the hours of the cafeteria. You could whip out a piece of watermelon, if you felt like having some.

I was scared stiff, too. It took me 3 days of being out of my mind before I could handle it, but I didn't know how I was going to really hack it when the real thing came. Also, my 5-year-old was there, still saying, the day before he died, "Where are the Rice Krispies?" And I was saying, "Well, dear, we don't have any Rice Krispies, have Cheerios." It was an ordinary time, too, and funny things still kept happening. The way one's family reacts is the way it is always going to react. I had been very close to Elizabeth, so I was there, and the two older kids were there blowing their noses, and Jennifer whipped her Kleenex over, and it made a basket into the wastebasket. Everyone clapped, and Chris, who was always getting dumped on in the family, blew his nose in a Kleenex and sort of threw it on the floor. His father said, "Chris, how can you be throwing Kleenex on the floor?"

Your family is going to have fights and they are going to have everything that they generally have. But you are also going to have an experience together that you can't have if you are afraid that a nurse is going to pop in the room at the next moment, or if you think you have to smile and look great.

[MR. MONTGOMERY]: Our son was 4 months old when he was diagnosed with AML, and the outlook was not good. We had talked a lot, I guess we all do, about what we would do "if." Our first relapse came, there was another remission, and we started talking about "what if," and thought we had it all pretty well worked out. When he had his first relapse, we worked with his physicians and we were able to give him treatments and keep him at home. It went so much better for us and for Seth, that we knew when the what-if's were over, having him at home was not only good for him but good for us. It gave us a sense of--not a sense, a real control of the situation which, unless you are treated in Dr. Wilbur's clinic or some of the other clinics I have heard about in the last couple of days, we did not find. Well, the "what if" happened, and the physicians told us he was relapsing, that we

had to rush him to the hospital. They were going to do this and that to relieve the pressure of the white cells in crisis, and we looked at each other, and once again, unsure of ourselves, yes, into the hospital he went. After an hour of some very unfortunate kinds of things, we looked again at each other, and our eyes told us that we had come to that point. We told them to stop, that we were going to take Seth home. Our decision was met with some disbelief. They finally asked us to wait until our physician could get there, which we did. Fortunately, he was very supportive, and relieved us of the inevitable fear. "Are we doing the right thing?"

He was terribly supportive, and said, "Yes, go right ahead, nothing can happen." We then were fortunate enough to get involved in the home care project, so we had Seth home. I think the things that others have done without this kind of support is testimony to the strength of parents. It was mighty nice at 1:30 in the morning when Seth was between us and just couldn't get to sleep, to pick up the phone, call up our nurse, and say. "Seth can't sleep, can you get something?" At 2:00 she was there, or before that, I am not sure. She came into the house. We were still in bed. She came upstairs in absolute darkness so she could give the injection. She just came into our bedroom, leaned over, and gave Seth a shot, excused herself, went downstairs. We found out later she stayed for another hour to find out if it would help before leaving. At 6:00 again we called because Seth's pain medication had worn off, and she was right back.

So we had a very short time, but it was a time of uninterrupted togetherness that I, as a father, particularly appreciated. I think many of us, fathers and mothers, find ourselves required to be out of the home for jobs and what not. For me, there was a lot of guilt because I would have to travel, and Kathy would have to handle everything by herself. So at least for those moments, we could be together completely, without interruptions, unless we asked for them. The home care project made that possible for us. Since it was a research project, there was no cost involved. In thinking about it, I did look back to our insurance policy to see if we could have afforded to do something like that on our own, and while I hope that Ida's work proliferates quickly, in our situation, I think it would have worked out all right.

We had an insurance policy with a basic program and then a major medical, so that at least 80 percent of the cost would have been picked up by the insurance and probably the medication and the injections would have been covered in full. In terms of cost it was certainly cheaper than care by physicians. It seems to me

that if Ida's figures stand up, it is a viable alternative in terms of cost, and certainly it is an alternative in our last moments.

Also, we walked away from it with a sense that we did everything we could. We are proud of the way we handled it, and that pride did a lot to ease the--help ease--the pain of that loss.

[Q]: In home care does the family call the physician or nurse to pronounce the body dead?

[MS. MONTGOMERY]: I think it varies from place to place. I think this is something maybe to share with parents, that there are problems that I think you should be aware of. In our case, the physician and nurse arranged that when Seth died the nurse would call the physician. She also called the coroner to report the incident. We live in Minneapolis, and there is evidently a law on the books that requires that the police come out when a person dies in the home to verify the cause of death. In our case this was to verify that we had not been abusive parents. We were not prepared for this. The physician tried to prevent it and asked the coronor to forego contacting the police, but the coroner opted not to, so we did have two policemen come into our home. I think you can imagine how awful it was. It was certainly one of the worst things I ever went through.

I am also certain that the two policemen who came in did not want to do it. It was a horrible experience for everyone involved, and people have started to work on this aspect. It is just something that parents should not be subjected to, and it is part of the certain arrangements that should be straightened out in advance, if you elect to take your child home.

During the time Seth was at home, my entire family--aunts, uncles, and cousins--had a chance to say good-bye to Seth in an atmosphere that was peaceful, as opposed to the hospital. It meant a lot to my daughter. I think it made her feel not so alone that she could share her grief. When it appeared that death was literally imminent, we told our daughter that Seth would die. She begged us to call the doctors, because she believed that they could fix him up again, as they had done so many times. We had to tell her that we felt utter defeat and there was no fixing up.

It was very difficult, but I think, as I look back at our relationship with our daughter, being honest with her, resulted in her having a great deal of trust in us.

[MS. WIDENER]: My name is Paula Widener, and I am from Dayton, Ohio. Our daughter, Margaret, was 14 years old. She was diagnosed with ALL in October of 1976, and we just lost her on March 14 of this year. Now, unlike the rest of our panel, we did not have Margaret at home when she died. Margaret entered the hospital on December 26, about 6:15 in the morning, and she was there except for a few days until March 14, so she had a lot of complications and a lot of problems.

I had thought about taking her home and keeping her home when we knew we weren't getting too far with the drugs. But one of my questions was that I felt home care with a nurse, and all of the equipment that was needed, would have been astronomical. In fact, being in the hospital proved astronomical moneywise, because our insurance was not that great.

I never gave up faith or hope that our daughter Margaret would make it. I never gave that up until she took her last breath. I have a strong belief in God. I don't push my religious beliefs off on anybody else, but I strongly believe in God.

When the doctors told us that Margaret was dying, for 3 days we thought that was it. But I still believed that God could do something about it, and He did, and we got to take Margaret home for a couple of days. I won't go into great detail about it, but never, ever, give up hope. Just because you hear someone talk about his experience with his child, and your child is still alive, there is always hope. Everybody's child is different. Everybody's circumstances are different.

The most important thing is to do what you feel is the right thing for yourself and for your child.

[MS. KEYSER]: There was a question before: What about your other kids, and how do they feel? I think there are two important things. You have to keep listening, and you have to keep talking. I had told Wendy--she was 3 when Sam was diagnosed--that Sam had leukemia. I had gone through the idea that she would probably not get leukemia, because if you took a whole sandpile, only one grain of sand was going to get leukemia. She then said, "How come we know so many kids with leukemia?" I said, "Well, we go to the clinic all the time."

Then, as the time got near, I told her everybody is working very hard, but Sam is going to die. Three days later she said, "Sam has not died yet." I said, "I know, sometimes it takes a little time." So the thing is, you just have to hang on, and keep listening to what they are saying. The other mistake I made with

Wendy was after he died. I thought I would grieve, but I wasn't prepared for how long she would grieve also, she said, "I was very nice to Sam." Now, really, I didn't know if Wendy or leukemia was going to do him in first, because she would jump up and down in the bed beside his head, and romp around to keep him entertained.

I said, "Wendy, you weren't always nice to Sam. Sometimes you were awful, and sometimes I was awful to you." One time I hit her so hard I nearly broke my hand, and I didn't know how I was going to go into a hospital and get my hand X-rayed from whacking my kid. So I told her I was very worried and sometimes I wasn't very nice, and she wasn't very nice, but we both loved Sam. She said, "I know. There just wasn't very much time to kiss him, was there?" and I said, "That's the thing about living we have to remember. There's not much time to waste in coming to each other." Right after that I saw her playing with other kids, and she was kissing one of them. That was kind of neat.

XIII. Medical/Ethical Problems Associated with Childhood Cancer

Leonard J. Emmerglick, M.D., J.D.

We are living in a society in which individualism as an ethic has come to cause people to focus inward upon themselves; to be less concerned with relationships with others. As a result, humanistic compassion is diminished. And this is apparent in all parts of our society including medicine.

Humanistic medicine, is what I shall be talking about this morning. Until a few years ago, the medical school curriculum consisted entirely of education in hard science. The humanities and medical ethics were conspicuously lacking from the curriculum. This lack became so evident in the kind of medicine some people were experiencing, and in the glaring disregard of patient rights in clinical research that the medical schools began to introduce courses on medical ethics into the curriculum. This subject is now being taught in more than 90 medical schools, and the number is increasing each year. A national commission was created to study the way in which research with human subjects might be made more ethical and humanistic, and its recommendations have produced new regulations by the Department of Health, Education, and Welfare relating to such research.

I believe that doctors want to be ethical and humanistic. Yet for the most part their training has not helped them much.

The great advances made by medical science in creating new capabilities, present to doctors and patients many difficult dilemmas. Cancer in children frequently presents parents with hard choices. They want good science, but above all, they want

medicine which is humanistic and ethical. They want a commitment by the doctor that what counts most is the unique human being, the unique child before him who is stricken with cancer.

Just what is the fundamental, ethical duty of the doctor? Can we describe this by the word "loyalty?" Can we describe it better by the word "faithfulness?" Is it better to call it a fiduciary relationship of trust and confidence? All of these and other possible definitions were considered by one of the leading bio-ethicists of our times, Dr. Paul Ramsey, a theologian at Princeton University. His exhaustive search finally brought him to the one word which he found to best describe the duty owed by the physician to the patient, the Hebrew word hesed, meaning loving kindness or steadfast love. This is indeed the quintessential nature of what is owed to the patient in this unique relationship, which stands alone among all of the possible relationships between human beings. Loving kindness is the measure of the ethical duty of the physician to patient.

When a doctor embarks upon human subject research he takes on a new loyalty, a loyalty to science. His primary duty of complete devotion to his patient now must be carried on along with a dedication to a research endeavor for the benefit of mankind. There are some who think that this creates too great a conflict of interest and that those engaged in patient care should not carry on clinical research. This is not the majority view, and in practice patient care is beneficially combined with research. But the conflict does exist and for this reason, in recent years, a body of regulations for clinical research on human subjects has come into being. Their application has shown that research can flourish and increase under their control. We can have research and ethics.

Should research be pursued vigorously in pediatric cancer? A general warning respecting the rate of progress which should be sought in clinical research was expressed once by Dr. Hans Jonas, a distinguished philosopher, in these words:

> Let us not forget that progress is an optional goal, not an unconditional commitment, and that its tempo in particular, compulsive as it may become, has nothing sacred about it. Let us also remember that a slower progress in the conquest of disease would not threaten society, and that society would indeed be threatened by the erosion of those moral values whose loss, a possibility caused by too ruthless a pursuit of scientific progress, would make its most dazzling triumphs not worth having.

As applied to large bodies of clinical research, this is undoubtedly true and sound. But cancer is a unique problem and there is a higher category than the abstract universal good for a society as a whole. That category, higher than the abstract universal, is the "concrete personal," the very child before you, stricken with cancer. Only by innovation, by new knowledge, by creative imagination will that concrete individual be saved ultimately. And so research is to be encouraged and supported and speeded, but it must also be carefully scrutinized and guided by ethical and humanistic standards.

The national commission I mentioned earlier made recommendations a few months ago for HEW regulations on research involving children. These regulations sought to resolve a long-time controversy respecting the submission of children to nontherapeutic procedures by the consent of their parents. This is a subject which has vexed the courts and legal writers without producing anything like a final judically adopted position. Distinguished jurists declared that under no circumstances would it be competent for parents to submit children to nontherapeutic studies. But here and there, support could be found for the thesis that where there were only minimal risks, parental consent would be legally, morally, and ethically appropriate.

The HEW regulations as proposed by the commission, adopt this view and go beyond it. When more than a minimal risk to children is presented by an intervention that does not hold out the prospect of direct benefit for the individual subject, it may be conducted if an institutional review board has determined that such risks present a minor increase over minimal risks and that the anticipated knowledge is of vital importance for understanding or amelioration of the subject's disorder or condition.

Many perplexing difficulties will arise in the effort to apply such broadened authority. Parents will have a role in the application of the new regulations such as they did not have before. They will be called upon to be present when many kinds of studies are carried out. They are to be involved in the research. An institutional review board may determine that small children should participate in certain types of research only if the parents participate themselves by being present during some or all of the research. Occasionally, a patient advocate has been appointed in research studies and in this way there was a larger prospect of insuring that they would be ethical in all respects. This practice is encouraged by the new regulations. They call for not only the soliciting of assent from children above 7 years of age, and older, but also the permission of both

parents and a monitoring of the solicitation of both assent and permission.

Parental consent is to reflect the collective judgment of the family, although there will be some situations, usually involving minimal risks, where the permission of only one parent will be sufficient.

There is another very important ethical duty to the child with cancer which is shared by physicians, nurses, and parents. It is a duty to take every measure which will instill, reinforce, and sustain hope in every child stricken with cancer. The motive for instilling and sustaining hope and the means selected to do it, have a special significance in cancer. I am speaking of something which goes beyond emotional support. I am speaking of the therapeutic power of hope and a positive attitude to often stimulate the immune system to more effectively combat cancer. It is my view that instilling and sustaining hope is not a matter of choice between optimism and pessimism, but a duty.

As I attempt to explain this thesis on this Sunday morning when you have just come from an ecumenical service, it is an interesting coincidence that I begin with a quotation from a commentary upon the Old Testament on the part of a Talmudic Rabbi who expressed the great insight: "God prepares the healing before the hurt." A human doctor, he went on to explain, prepares and applies the poultice only after a wound comes about. Not so God, said this sage, God has implanted the healing into the body. This insight preceded by many centuries what science tells us today that each one of us, from the womb onward, has an immune system built into our bodies which works to protect us from harmful bacteria and viruses and to heal our infections and diseases. It is a respectable hypothesis, held by many researchers and clinicians, that ordinarily in the process of cellular division there are cell mistakes, and for this and other reasons we all make cancer cells; and the immune system kills them. But if the immune system is numerically overwhelmed or becomes for some reason weakened, or a cancer cell slips by, a cancerous tumor or malignant disease results.

Experimental studies are going forward to stimulate the immune system of patients with some types of cancer. Some encouraging results have been achieved. Quite apart from the results of such studies, for many years it has been known that spontaneous remissions occur in cancer; tumors disappear or the progress of the disease is so slowed that there is a long remission. Only some of the cases where tumors disappear can be attributed to the chance occurrence in the cancer patient of an infection. Then

the body's immune system creates antibodies which attack and kill the infecting virus or bacterium and at the same time attack and kill the cancer cells and destroy the tumor.

A considerable amount of medical literature attributes many spontaneous cures or remissions to a hopeful, positive fighting attitude, which probably stimulates hormonal secretions, which in turn stimulate the immune system. Hopefulness must be imbued and sustained in the child and in all of those concerned in his or her care. As long as this possibility of stimulating the immune system exists, and unless all of the evidence of involvement of the immune system in cancer is to be rejected, hope is a duty.

So let us take heart and promote pediatric cancer research because children are the most important, hopeful beings on the face of the earth. In a world in which we see wide areas of business and industry and labor to be corrupt; government to be ineffective to deal with inflation, an energy crisis, and social ills; a world in which we have schools which do not educate, courts which do not administer equal justice, medicine which does not deliver health care; a world in which our economy, based only on the pursuit of self-interest, produces great wealth and beside it great poverty; meager salaries for teachers but millions for rock music singers--I could go on and on--in this world of ours, our hope is only in our children to restore an attachment to a spiritual way of life. So we must heal them, save them for life, by research, ever more research.

Until now every child's struggle with cancer was wrestling in the dark with an unknown masked destroyer. But the fruits of research will enable us increasingly to tear the mask from Death's stony face and take back from his hand the flickering torch of life, and make it glow again and light the darkness with its brilliance.

Appendix A—Conference Participants

Speakers and Moderators

Mary Ann Allen, Medical College of Virginia, Richmond, Virginia

Fred W. Bender, Psychologist, Northwestern University, Chicago, Illinois

Toby Bogorff, Candlelighters, Fort Lauderdale, Florida

Karen Briscoe, Mid-American Cancer Center, Kansas City, Kansas

Jeanette Charniak, Private Pediatric Hematology/Oncology Clinic, Green Bay, Wisconsin

R. Lee Clark, M.D., President, University of Texas System Cancer Center, M. D. Anderson Hospital and Tumor Institute, Houston, Texas; Past President, American Cancer Society

June Crockett, Educational Consultant, University of Virginia Medical School, Charlottesville, Virginia

Chris de Laurier, SanDaCC, San Diego, California

Leonard J. Emmerglick, Professor of Oncology and Family Medicine, Professor of Law Emeritus, University of Miami Law School, Coral Gables, Florida

Edwin N. Forman, M.D., Director, Pediatric/Hematology/Oncology, Associate Professor of Pediatrics, Brown University, Providence, Rhode Island

Richard A. Gephardt, Congressman, St. Louis, Missouri

Barbara Hellenack, IMPACT, Matawan, New Jersey

Robert I. Henkin, M.D., Director, Center for Molecular Nutrition in Sensory Disorders, Georgetown Hospital, Washington, D.C.

Sharon Hostler, M.D., Associate Professor of Pediatrics, University of Virginia Medical School, Charlottesville, Virginia

Carmault B. Jackson, Jr., M.D., Associate Director, Extramural Program, University of Texas System Cancer Center, Houston, Texas

Gerald G. Jampolsky, M.D., Consultant, Center for Attitudinal Healing, Tiburon, California

Susan Lawrence, Metropolitan Washington Candlelighters, Silver Spring, Maryland

Richard H. Lucas, Ph.D., Assistant Professor of Pediatrics (Psychology), University of Texas System Cancer Center, Houston, Texas

Ida M. Martinson, R.N., Ph.D., F.A.A.N., Professor, Director of Research, University of Minnesota School of Nursing, Minneapolis, Minnesota

Grace Powers Monaco, J.D., President, Candlelighters Foundation, Washington, D.C.

Jay and Kathy Montgomery, Candlelighters, Minneapolis, Minnesota

Gary R. Morrow, Ph.D., Assistant Professor of Oncology in Psychiatry (Psychology), University of Rochester Medical Center, Rochester, New York

Helen Newman, Candlelighters, Stamford, Connecticut

David G. Poplack, M.D., Senior Investigator, Pediatric Oncology Branch, National Cancer Institute, Bethesda, Maryland

Carey Randall, Metropolitan Washington Candlelighters, McLean, Virginia

Aaron R. Rausen, M.D., Director of Pediatrics, Beth Israel Hospital, Professor of Pediatrics, Mt. Sinai School of Medicine, New York, New York

Catherine Russell, Leukemia Society Outreach Program, Boston, Massachusetts

Donald B. Schwartz, M.D., Co-Director, Division of Hematology/Oncology, Children's Hospital and Health Center, San Diego, California

Genie W. Schweers, Rhode Island Hospital, Providence, Rhode Island

Sue Spratt, P.A.T.H., West Kingston, Rhode Island

Julie Sullivan, National Conference Chairperson, Candlelighters Foundation, Washington, D.C.

Sister Margaret Weeke, SSM, Cardinal Glennon Memorial Hospital, St. Louis, Missouri

Jordan R. Wilbur, M.D., Director, Children's Cancer Research Institute, San Francisco, California

Norma Wollner, M.D., Attending Pediatrician, Memorial Sloan Kettering Cancer Center, New York, New York

Panel Members

TEENAGER REACTOR PANEL MEMBERS

Ashley Brown - Alberta, Canada
Jill Chapman - St. Louis Candlelighters, St. Louis, Mo.
Ken Daniels - St. Louis, Mo.
Eddie Kimball - Ottawa, Kan.
Janet Lanigan - St. Louis Candlelighters, St. Louis, Mo.
Valerie Nelcamp - Cincinnati, Ohio
Nicholas Quiroz - St. Louis, Mo.
Malcolm Schorlemer - San Antonio, Tx.
Debra Vehlewald - St. Louis, Mo.

LONG-TERM SURVIVAL

Marjorie Levy - Fairhaven, N.J.
Chris and Les Neagle - Sussex, N.J.
Dianne Neumann - New Canaan, Conn.
Merrianne Reagin - Danbury, Conn.
Sue Whitford - Phoenixville, Pa.

PARENTS AND THE TREATMENT PROCESS

Ms. Jan Black - Liberty, Mo.
Rev. Richard P. Chasse - Glen Allen, Va.
Ms. Edwina Eddy - Quebec, Canada
Ms. Yolande Marioles - San Antonio, Tx.
Ms. Susan Robinson - Alberta, Canada
Mr. Lee Sturm - St. Louis, Mo.

DISCIPLINE

Mr. James Kuba - St. Louis, Mo.
Ms. Joan Patterson - Gresham, Ore.
Mr. and Mrs. James Robb - O'Fallon, Mo.

NUTRITION

Ms. Pat Condron - Dayton, Ohio
Ms. Barbara Jaeger - Affton, Mo.
Ms. Susan Lawrence - Silver Spring, Md.
Ms. Trudi Thomson - Terre Haute, Ind.

COST OF CANCER

Ms. Mary Armstrong - San Antonio, Tx.
Ms. Barbara Lederer - Wauwatosa, Wis.

HOME CARE FOR THE DYING CHILD

Ms. Marty Keyser - Churchville, Pa.
Ms. Emily Kulencamp - Roseville, Minn.
Ms. Ceasar Reyes, Jr. - Marshfield, Wis.
Mr. Jerry Weidner - Kettering, Ohio

MEDICAL/ETHICAL

Ms. Vivian Elios - Hollywood, Fla.
Rev. Joseph Leggieri - Drexel Hill, Pa.
Ms. Judy McTavish, R.N. - Albert, Canada
Ms. Catherine Russell - Hudson, Mass.
Ms. Genie W. Schweers - West Kingston, R.I.
Ms. Roberta Stoiber - New Berlin, Wis.

Appendix B —Annotated Bibliography

Richard Lucas, Ph.D.

(I make no claim that these are the best books and articles. They are simply books which I have found helpful for myself and which parents have used and found helpful.)

Axline, V.M. Play Therapy. New York: Ballantine Books, Inc., 1969.

More for the advanced reader, this book explores how to let a child discover himself with an adult who is willing to accept the child as he is.

Axline, V.M. Dibbs: In Search of Self. New York: Ballantine Books, Inc., 1976.

This is a first-rate novel of a child many thought hopeless who learrs to discover both himself and his world. Although not particularly relevant to the child with cancer, it is a book of hope that is so sensitively written that any parent can enjoy its meaning.

Barnebey, N., and E. Ruppert, "Parents of Chronically Ill or Handicapped Children." In L.E. Arnold, ed. Helping Parents Help Their Children. New York: Brunner/Mazel, Publishers, 1978, pp. 174-182.

This article is very good on how to incorporate medical realities with child rearing.

Becker, W.C. Parents Are Teachers. Champaign, Illinois: Research Press, 1971.
This is a very basic "how to" book. It is a primer of behavior modification for parents with a lot of practical examples on how to reward and punish.

Bruch, H. Don't Be Afraid of Your Child. New York: Farrar, Straus, and Young, 1952.
This is a book for those who get confused (as we all do) about the many theories of child-rearing. Dr. Bruch explains that many parents become guilty and fearful about how to raise their children because they get too caught up in the "right" way or the need to have "special" techniques. It is a common-sense approach written by a very experienced psychotherapist.

Dodson, F. How to Parent. Los Angeles: Nash Publishing, 1970.
and: How to Father. Los Angeles: Nash Publishing, 1974.
These two books, especially the first, have become quite popular. Dr. Dodson assumes that parents need to learn how to be parents. His approach is to explain parenting according to the stages of development of your child. It is practical and can be used as a reference book according to the child's age.

Dreikurs, R. Coping with Children's Misbehavior. New York: Hawthorne Books, Inc., 1972.
This book looks at the child from a viewpoint of understanding the child's goal when he misbehaves. It is important reading for any parent who wants to have a deeper understanding of children and their relationships with adults.

Erikson, E.H. Identity, Youth, and Crisis. New York: W.W. Norton and Company, Inc., 1968.
This is not a book about child-rearing or discipline. However, Chapter III looks at how children develop according to tasks they need to master at each stage of their development. It is difficult reading at times, but the basic principles are well worth understanding.

Ginott, H.G. Between Parent and Child. New York: Avon Books, 1965.

Dr. Ginott explains how to talk with children by truly listening to what they say. Using his principles of communicating with children he offers practical advice on handling usual discipline problems. He teaches you how to be positive and encouraging and still set limits. Dr. Ginott has also written Between Parent and Teenager, and Between Parent and Parent.

Gordon, T. Parent Effectiveness Training. New York: Plume, New American Library, 1970.

This approach, which has gained popularity through courses and seminars, explains how to stop, look, and listen to your child. It emphasizes how to stop getting caught in win-lose battles with your child and create situations where both you and your child can win.

Holt, J. Escape from Childhood. New York: Ballantine, 1974.

This is not really a book on child-rearing techniques. However, Dr. Holt, who has written many books on children, talks about the potentials inherent in children. He sees children as being much more capable that we usually allow them to be.

Holt, J. "The Right of Children to Informed Consent." In J. van Eys ed. Research on Children. Baltimore: University Park Press, 1978, pp.5-16.

This is an article in a book about research on the child with cancer. Dr. Holt continues his theme that children naturally want to grow up to be adults, hence, they want to know what our rules are.

Kubler-Ross, E. Helping Parents Help Their Children. New York: Brunner/Mazel Publishers, 1978, pp.270-278.

This short article, written by the best known expert in "death and dying," talks about problems of denial and how children can tell us about living in their approach to dying.

Patterson, G.R. Families: Application of Social Learning to Family Life. (Revised). Champaign, Illinois: Research Press, 1971 (1975).

This book extends the basic principles in W.C. Becker (above) to the whole family. It shows how parents and children change each other's behavior by what they do. It talks about how rewards and punishments should and should not be used. It gives very practical examples and exercises.

Satir, V. People Making. Palo Alto: Science and Behavior Books, Inc., 1972.

This is a fun book about families. But it is so rich and insightful that you will see yourself and your family pop out of the pages at you. It talks about issues of self-worth, communication, rules families create, and how the family functions as a total system in meeting society. It shows how we create problems by not facing ourselves. It is a book the whole family can read together and can begin doing some of the family exercises Dr. Satir suggests.

Wood, S.J., R.S. Bishop, D. Cohen, Parenting: Four Patterns of Child-rearing. New York: Hart Publishing Company, Inc., 1978.

This is not a "how to" book in itself. Rather, it explains four basic approaches to child-rearing by examining the underlying assumptions, techniques, and pitfalls of each. It is a book spouses should read together because it is really about understanding yourself and your approach to child-rearing. It asks you to understand your values by looking at what you believe about your family, yourself, and your child.

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Fred W. Bender

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